Community
Development
& Health Network

Final
Report
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Our Lives, Our Meds, Our Health

Exploring medication safety through a social lens

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Foreword by the Chief Pharmaceutical Officer

Safety matters with medication. Medicines are the most commonly used medical intervention in Northern Ireland, and at any one time 70% of our people take prescribed or over the counter medicines, to treat or prevent ill health. In Northern Ireland, we are fortunate to benefit from effective systems for the safe prescribing, dispensing and administration of medicines. However, we know that errors can still occur, as in any walk of life, and we are committed to supporting improvements that aim to reduce or prevent the risk of harm related to medicines to patients and the public.

The Department of Health has a long and successful history of working in partnership with communities and local community pharmacies to address health inequalities. This research used a collaborative approach which ensured that the voices of people with direct experience of using health and social care services and medicines were heard as well as those who work in health and social care.

The evidence in this research provides the opportunity to learn about how people’s everyday lives and social circumstances can impact on their ability to take medication as prescribed and inspire us to drive improvements in medication safety. The report recommendations will further inform the implementation of the strategy ‘Transforming Medication Safety in Northern Ireland’ to improve safe practices with medicines and support a medication safety culture within our population.

Cathy Harri

Professor Cathy Harrison

Chief Pharmaceutical Officer

Department of Health

June 2023

About Community Development and Health Network (CDHN)

With over 2,300 members supporting tens of thousands of people, CDHN is Northern Ireland's leading organisation working to empower communities, improve health and wellbeing and reduce health inequalities. CDHN raises awareness of the root causes of poor health and health inequalities. We reshape the dominant narrative about the causes and solutions to health inequalities and how to improve health. Through our work, communities and decision makers are supported to recognise and utilise assets, to work together to develop solutions, take action to improve lives, health and wellbeing and create a fairer, more equal society.

For the last 29 years, CDHN has engaged with communities to design, develop, deliver, facilitate, and evaluate initiatives that improve health and address health inequalities. We recognise, value, and gather evidence to understand the social determinants of health and people's lived experiences. This is central to the development of initiatives and influencing policy to address health inequalities.

Acknowledgements

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- The Medication Safety NI Awareness Raising Working Group (ARWG) and TMSNI Programme Team
- CDHN staff team and Board
- Health and Social Care Trust Local Collaborators
- Voluntary Community and Social Enterprise (VCSE) survey respondents
- VCSE and Health and Social Care stakeholder interviewees
- Focus group host organisations in the community and voluntary sector
- Dr Joanna Dowd
- Community Medication Safety Research steering group, including:
  - Joan Smith, Service User
  - Aileen McGuinness, Bogside and Brandywell Health Forum
  - Tracey Ritchie, Inspire Wellbeing
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  - Carmel Darcy, Medicines Optimisation for Older People (MOOP)
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Lastly, we want to express our immense gratitude to **each focus group participant**, as this research would not have been possible without their invaluable contributions.

Contents

Abbreviations

ARWG	Awareness Raising Working Group
CBPR	Community-Based Participatory Research
CDHN	Community Development and Health Network
DoH	Department of Health, Northern Ireland
GP	General practitioner
HSC	Health and social care
HSCB	Health and Social Care Board
HSCT	Health and Social Care Trust
ICS	Integrated Care System
KCA	Know, Check, Ask
KEW	Knowledge Exchange Workshop
NCD	Noncommunicable diseases
NI	Northern Ireland
NISRA	Northern Ireland Statistical and Research Agency
OTC	Over the counter
PSNI	Police Service of Northern Ireland
NICE	National Institute for Health and Care Excellence
SDOH	Social Determinants of Health
SMR	Structured Medication Reviews
SPPG	Strategic Planning and Performance Group DoH (Formerly Health and Social Care Board)
TMSNI	Transforming Medication Safety in Northern Ireland
UK	United Kingdom
VCSE	Voluntary, Community or Social Enterprise organisation
WHO	World Health Organization

1. Introduction

This research addresses a gap in the evidence base on how social determinants of health (SDOH) impact medication safety in Northern Ireland (NI). The study was undertaken by the Community Development and Health Network (CDHN) and commissioned by the Department of Health Strategic Planning and Performance Group (SPPG) (formerly known as Health and Social Care Board)[i] as part of the Transforming Medication Safety in Northern Ireland (TMSNI) plan[1].

Research on health inequalities shows that health and illness follow a social gradient; the lower a person's socioeconomic position, the worse their health. This downward slope is the product of the Social Determinants of Health (SDOH),[2] which have a larger impact on health outcomes than genetic makeup or lifestyle behaviours. Social circumstances constrain individuals' ability to change[3].

The Department of Health (DoH) launched the TMSNI plan (2020) in response to the World Health Organisation's (WHO) Third Global Patient Safety Challenge, 'Medication without Harm'[4]. Know, Check, Ask (KCA) is a medication safety campaign developed by WHO and adapted by DoH as part of the plan[ii]. CDHN were asked by DoH to include a critical reflection of the KCA campaign as part of the research objectives.

CDHN is NI's leading organisation working to empower communities, improve health and wellbeing and reduce health inequalities. We recognise, value, and gather evidence to understand the social determinants of health and reflect on people's lived experiences. It is with this expertise that we delivered this research project.

Research Aim

> *Discover the social circumstances behind unsafe medication practices and avoidable medication-related harm to inform the implementation of the TMSNI plan using a community-based participatory research (CBPR) approach.*

Research objectives

The overall objective was to engage with key stakeholders (people in the community, voluntary, community and social enterprises (VCSE) organisations, healthcare professionals, and those working in government and academia) to gather evidence and perspectives about the extent of unsafe medication practice; the social circumstances and health inequalities that impact on medication related harm; and gain their support for the work.

1. To **increase awareness** of medication related harm and the current supports available to promote the WHO inspired Medication safety challenge and critically reflect on the Know, Check, Ask campaign.

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[i] Commissioned under the Supporting Medicines Safety Action Plan for Northern Ireland (NI) (Awareness Raising Working Group ARWG) The HSC Board (HSCB) closed on 31 March 2022 and responsibility for its functions transferred to the Department of Health as the Strategic Planning and Performance Group (SPPG).

[ii] Adapted by Department of Health (DoH) for NI, the campaign was initially launched in NI in May 2022 as part of the Pharmacy Living Well Service and was rolled out across all healthcare sectors in September 2022

2. To **explore** with people from (a) **socially disadvantaged communities** and (b) **identified groups more at risk** of medication related harm the social circumstances behind unsafe medication practices, barriers to making decisions about medication, and barriers on reporting medication issues.
3. To **explore with Health and Social Care (HSC) staff** their experiences of the social circumstances behind unsafe medication practices; barriers to making decisions about medication; and barriers on reporting medication issues.
4. To identify **potential solutions** to support the development and future roll out of targeted Medication Safety communications campaign, awareness raising for patients and the public, staff training and any additional guidance or information.
5. To **disseminate the findings** to inform the implementation of the medication safety plan, in particular the public awareness campaign and training of HSC staff.

Chapter 2 is a literature review on social determinants of health and medication safety. This is followed by Chapter 3, which outlines the CBPR methodology approach used. Chapter 4 then presents the focus group's findings under six key themes: social determinants of health, health literacy, reporting errors and concerns about medication, making decisions about medication, health, and social care and the Know, Check, Ask medication safety campaign[5]. Chapter 5 is a discussion of the findings with relevance made to previous research. Finally, Chapter 6 details recommendations to ensure social factors are given recognition in the future delivery of TSMNI action plans.

2. Literature Review

This literature review provides an overview of the literature on health inequalities and the social determinants of health, social deprivation and medication, health literacy and medication use, harm, and issues. The review provided a rationale and context for the research and helped refine the research questions and methodology.

Health inequalities and the Social Determinants of Health

Health inequalities are the unfair and avoidable differences in the health of people in our society. They refer to the unfair nature of health differences between social groups brought about by the conditions in which they are born and live. They are avoidable as these differences do not happen randomly but are determined by social factors that are largely out of an individual's control.

In NI, people from the most disadvantaged communities suffer a heavier burden of illness and have higher mortality rates than people from the least deprived[6.] The Marmot Review[7,] demonstrates the social gradient of health inequalities; the lower a person's social and economic status, the poorer their health will likely be. This social gradient in health runs from top to bottom of the socioeconomic spectrum, meaning that health inequalities affect everyone.

The downward slope in the gradient is the product of the Social Determinants of Health (SDOH). The SDOH are the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow up, live, work and age, and the broader set of forces (economics, social policies, and politics) and the systems put in place to deal with illness that shape the conditions of daily life.[8] Some key social determinants are education and employment opportunities, housing, social support, income, employment, your community, and access to health services.

Marmot3 demonstrates that the SDOH have a bigger impact on health outcomes than genetic makeup or lifestyle behaviours. The social gradient in health clearly implies that action to improve health and reduce inequalities must occur at a societal level, not simply depending on individuals making lifestyle changes. Social circumstances constrain an individual's ability to change, actions targeting individual changes will only have a limited impact in supporting people who experience social and economic disadvantage, to lead healthier lives.

The WHO Global Commission on the Social Determinants of Health[9] identified three areas for critical action in tackling inequalities in health:

1. Improve daily living conditions; (the circumstances in which people are born, grow, live, work and age)
2. Tackle the inequitable distribution of power, money, and resources (The structural drivers of those conditions of daily life)
3. Measure and understand the problem and assess the impact of action (Expand the knowledge base, develop a workforce that is trained in the social determinants of health, and raise public awareness about the social determinants of health)

Social deprivation and medication in Northern Ireland

Data from NI General Pharmaceutical Services 2021/22 show that the number of prescription items dispensed is almost 50% higher in the most deprived areas in NI compared with the least deprived. As seen in Figure 1, those living in the most deprived areas in NI were dispensed more diabetes medication/products, anti-depressants, and opioid analgesics (medication for pain relief) than the NI average. Notably, the number of items prescribed reduced as the levels of deprivation reduced. For example, in the most deprived areas, 25.4% of people were dispensed anti-depressants compared to 16.4% in the least deprived[10].

Deprivation Quintile	Diabetes medication/products	Anti-depressants	Opioid analgesics
1 - Most Deprived	6.3%	25.4%	6.8%
2	5.8%	20.8%	5.9%
3	5.3%	18.2%	5.1%
4	5.1%	17.5%	4.6%
5 - Least Deprived	4.7%	16.4%	4.2%
Northern Ireland	**5.4%**	**19.6%**	**5.3%**

Figure 1: Proportion of population whom antidepressants, diabetes medication/products and opioid analgesics were dispensed by financial year and deprivation quintile

According to the Lancet, conflict-related traumatic experiences among the Northern Ireland population as a result of the Troubles contribute to the greater prevalence of mental health issues in NI compared to other UK nations. While the current population are less likely to have experienced direct conflict, it is acknowledged that transgenerational trauma could play a role[11].

Other qualitative research also supports the data connecting prescription rates and deprivation. There is a link between a higher prevalence of diabetes and social factors such as poor transport and high unemployment rates, which are associated with living in areas of deprivation. A low income can also mean it can be more difficult for people with diabetes to buy healthy foods to help manage their condition[12]. Social factors associated with anti-depressant prescription include social deprivation, ethnic density and socio-economic status [13]. This research supports the link between social factors, including social deprivation, and increased medication use.

Polypharmacy can be defined as the routine use of four or more over the counter, prescription and/or traditional medications simultaneously by a patient and is known to contribute to medication safety risks[14]. Polypharmacy has increased dramatically with increased life expectancy in the general population and older people living with several chronic diseases[15]. In NI, 32% of patients receiving 5 or more medicines have prescribing or monitoring errors, increasing to 47% in patients receiving 10 or more medicines[1]. The TMSNI plan commits to reducing unnecessary polypharmacy by ensuring that all patients most at risk of harm receive an annual medical review. The SIMPATHY Consortium reports that the percentage of patients prescribed ten or more medicines increases with deprivation[16], highlighting a cause for concern in the potential of errors in those living in deprivation.

Furthermore, Northern Ireland Statistics and Research Agency (NISRA) 2010-2020 statistics show that drug-related deaths are notably higher in areas of deprivation across NI, with those living in deprived areas five times more likely to die from a drug-related death than those in the least deprived areas[17].

Social determinants of health and medication safety

There is a dearth of studies on the social determinants of health and its relationship to medication safety and medication adherence. No studies of this nature could be found in the NI population. Some research findings from England and Scotland and international research are presented below.

A recent article in the Pharmaceutical Journal[18] describes how the under-reporting of patient safety incidents at home, including medication errors, presents a problem to our understanding of the scale of the medicine safety issue. The article reports that a significant number of errors, and subsequent harm, are being missed by the conventional methods of reporting patient safety incidents. Families also have faced many challenges that may be contributing to errors. These include age-inappropriate formulations; the timing of doses outside of waking hours; difficulty in measuring doses; use of unlicensed medicines; and inadequacy of medicines information.[19]

A qualitative study on the lived experiences of a cohort of older adults in Brighton and Hove in England looked at medication use and found that social factors that prevented safe medication practice included a lack of comprehensible information provision and age-related adherence issues[20]. Individuals' expectations of how medication works can be influenced by prejudices relating to the physical characteristics of the medication, and information from family and friends. The prescribed purpose of medications can also be undermined as some UK adults perceive skipping doses as harmless [21].

A study in Scotland found social deprivation to be a characteristic of those who had low adherence to medication regimens compared to those who were highly adherent[22]. International studies have identified how social circumstances can influence medication safety and medication adherence. Regarding social deprivation, neighbourhood deprivation has been related to increases in medication prescriptions, independent of individual-level sociodemographic characteristics[23]. Similarly, as social deprivation increased, potentially inappropriate medication use increased[24]. Other social factors associated with medication non-adherence include social support[25], socioeconomic status[26], income[27], and lifestyle choices[28].

A report by The Kings Fund[29] explains that many people consider that they have little control over whether and how they use their medicines. It describes that while many patients adapt to long-term medicines use, others find that their regimen's demands are detrimental to their quality of life. For these reasons, the patient's perspective on medication-taking must be recorded. A recent systematic review found a significant relationship between social determinants and medicine adherence and concluded that the relationship warrants more attention from healthcare providers and policy makers[30].

Health literacy

Health literacy has been recognised as a social determinant of health[31]. Anyone can have low health literacy. However, people and population groups with limited financial and social resources are likelier to have low health literacy. Health literacy contributes to health inequalities because the population groups most at risk of low health literacy are also known to have the poorest health outcomes. In Northern Ireland, the HSC Regional Health Literacy Forum use the following definition of health literacy:

> *"Health literacy is about our knowledge, skills, understanding and confidence to be able to use health and care information and services to make good health decisions*[iii,32,33]

In 2022, WHO's report on health literacy and non-communicable diseases (NCDs) includes a new definition of health literacy[34]:

> *"The personal knowledge and competencies that accumulate through daily activities and social interactions and across generations. Personal knowledge and competencies are mediated by the organisational structures and availability of resources that enable people to access, understand, appraise and use information and services in ways that promote and maintain good health and well-being for themselves and those around them".*

The WHO report describes how people rarely make health decisions in isolation but instead through interaction and support from other people, institutions and organisations, services, and systems. The report emphasises the importance of understanding health literacy as a social practice where health decisions and the ability to maintain healthy behaviours, are determined by powerful and unique community norms and cultures, and organisational and political factors impacting communities.

Research has shown that people with higher levels of health literacy feel better equipped to be active partners in their health care, navigate healthcare systems effectively and advocate to political leaders and policymakers[35]. Previous research has also shown that limited health literacy is associated with less recall and adherence to medical instructions and self-care regimes and more negative beliefs about medication, such as fear of medicines[36]. It is suggested that healthcare professionals should be more aware of health literacy, including knowledge of the concept and identifying those who have poor medication literacy and need support[37]. Improving health literacy can result in improved health outcomes for the individual, better patient and professional relationships, more appropriate use of HSC services and reduced health inequalities[38].

Medication use in NI

In NI, medicines are typically obtained via a prescription or purchased over the counter (OTC), and all prescriptions dispensed are free of charge[39]. Compared with other UK countries, NI's volume and cost of medicines used per head of population are historically higher[40].

With an estimated population of 1.9 million people[41], every year in NI, 43.2 million prescription items are dispensed through community pharmacies and a further 2.4 million inpatient prescription items

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[iii] The definition was co-produced by the Western Health Literacy Delivery Group with service users in Northern Health and Social Care Trust and has been agreed to be used by members of the HSC Regional Health Literacy Forum.

are dispensed in secondary care[1]. Overall, it is estimated that at any one time, 70% of people in NI take prescribed or over the counter medicines to treat or prevent ill health[40].

Medication-related harm

Medication errors can occur at any point in the medication cycle – prescribing, dispensing, administering, monitoring and/or use. In 2016 the WHO used the following definition of a medication error;

> *"Any preventable event that may cause or lead to inappropriate medication use or patient harm while the medication is in the control of the health care professional, patient, or consumer. Such events may be related to professional practise, health care products, procedures, and systems, including prescribing, order communication, product labelling, packaging, and nomenclature, compounding, dispensing, distribution, administration, education, monitoring, and use"*[42].

Around one in 30 patients experience preventable medication harm in medical care-; more than a quarter of this harm is considered severe or life-threatening[43].

Medicine adherence in NI

It is reported that only 16% of patients prescribed a new medicine in NI take it as prescribed, experience no problems, and receive as much information as they need[1]. Avoidable medication related adverse events are thought to lead to 800 non-elective hospital admissions in NI every year, consuming 5,500 bed days at the cost of £1.9million to HSC. These statistics highlight the costs of medication errors to population health and the health service.

Reporting issues and concerns about medication

Most of the international literature on reporting medication errors discusses the perspective of HSC staff concerning prescribing and monitoring errors and in primary and secondary care settings[44,45]. However, a study in Africa suggests barriers to patients reporting errors and concerns include poor healthcare systems, fear of consequences of reporting, lack of time to report, and lack of health literacy/knowledge[46].

Members of the public can return unwanted medication to any community pharmacy in NI for safe disposal[47]. Alternatively, Remove All Prescription and Illegal Drugs (RAPID) is a community-led initiative supported by the Police Service of Northern Ireland (PSNI) and the Public Health Agency that raises awareness of the harm associated with using and misusing drugs and promotes the removal of unwanted/expired/ prescription medication from local communities. Yellow RAPID bins are in multiple local community locations in NI. Prescription medication makes up 90% of the items disposed of in the RAPID bins, highlighting the benefits of its place within communities to improve medication safety.

There is currently no known research on reporting medication errors and concerns in NI from either the patient or the public perspective. Yet, it is essential to understand and address any barriers, as reporting medication errors is crucial to maintaining the safety of users. Regular reporting is also encouraged, allowing HSC staff to learn and improve to prevent future errors[48].

Making decisions about medication

Medication reviews

Medication reviews can have several interpretations and are carried out with people of all ages. There are also other types which vary in their quality and effectiveness. In the National Institute for Health and Care Excellence (NICE) guidelines, 'medication review' is defined as:

> ' *A structured, critical examination of a person's medicines with the objective of reaching an agreement with the person about treatment, optimising the impact of medicines, minimising the number of medication-related problems and reducing waste*'.

Different health professionals can carry out reviews. Based on their knowledge and skills, it may be led, for example, by a pharmacist or an appropriate health professional who is part of a multidisciplinary team. The NICE guideline states medicine reviews as a method of medicines optimisation: the effective use of medicines to enable the best possible outcomes[49], highlighting their importance in medicines adherence.

Shared decision making

In 2021 NICE's guidance on shared decision making[50] notes that although the benefits of shared decision making are increasingly recognised, it is not yet routinely practised in every setting, and definitions of what constitutes shared decision making can vary.

However, steps have been taken towards ensuring people are involved in shared decision making in NI. The DoH and HSC recently co-produced guidance on shared decision making, using the following definition:

> *"Shared decision making is a practice in which a person receiving care and a person providing care work jointly to make decisions. It brings together the expertise and experience of both, enabling each to understand what is important when choosing a course of action. By working together, we make the best treatment and care decisions for each individual"* [51]

In the guidance, they note that a person may choose to include their family, carer, or advocate in the conversation to build a shared understanding of what is important to them and help with the decisions to be made. When the decision involves a child or young person under 18, their parent or carer will be involved. Shared decision making is evidence of the values of HSC in practice.

iSIMPATHY[52] was an EU-funded project which ran from October 2019 to March 2023 across the three jurisdictions of Northern Ireland, Scotland, and the border areas of Ireland. It sought to transform the approach to optimisation of medicines through the delivery of medicine reviews to over 6,000 patients taking multiple medications, and in delivering training to 120 GPs, hospital doctors and pharmacists. The final evaluation is in development.

The Health Survey NI 2021/22 states that half of people prescribed medication felt fully involved in decisions about the best medication for them[53]; however, there is currently no qualitative research on experiences of making decisions, and what influences people to participate/not participate in making decisions about their medication.

Non-pharmacological alternatives to medication

A recent OECD report[65] notes that the healthcare system is structured mainly around using medicines to treat and manage disease. While medications are the only effective treatment for some conditions, relying on medication as the initial or sole approach to disease management exposes patients to excessive risk.   It also states that across some conditions, an emerging evidence base points towards non-pharmacologic interventions that are equally effective and pose less risk to patients. It is therefore essential to understand and address the barriers to the uptake of these alternatives[65] to reduce overprescribing (the prescribing of excessive or unnecessary medication)[64].

Research has found that people want more information about alternatives to medication, including lower doses, changing medication, or other options such as herbal medicines/ supplements/ homoeopathy. It was also suggested that introducing a conversation between patients and the public and healthcare professionals could encourage the patient's responsibility and self-management of the medication[54], which in turn could support adherence.

Social prescribing is a possible avenue for accessing alternatives to medication. It is an innovative and growing movement and is at a relatively early stage of development in NI. Nonetheless, the potential of social prescribing in improving health outcomes is recognised by HSC and the Department of Health[50]. The All-Ireland Social Prescribing network defines it as:

> *"Social Prescribing is a means of enabling GPs and other frontline healthcare professionals to refer patients to a Social Prescriber/Link Worker - to provide them with a face to face conversation during which they can learn about possibilities and design their own personalised solutions (i.e. 'co-produce' their 'social prescription') so that people with social, emotional or practical needs are empowered to find solutions which will improve their health and wellbeing, often using services provided by the community and voluntary sector"*[55]

Examples of social prescribing interventions include exercise classes/groups, nutrition interventions, employment/volunteer opportunities, and community activities such as gardening and sports. These interventions are said to have a clear biomedical intent, for example, exercise classes/groups to reduce the dependence on medication among people with diabetes[56]. Previous qualitative research showed that social prescribing interventions were perceived as having the potential for long-term benefits compared to medication. After a discussion with their General Practitioner (GP), people were also found to understand the potential benefits of social prescribing including reducing medication. Therefore, good communication between patients and referrers is crucial for patient uptake[57].

3. Methodology

Community-Based Participatory Research (CBPR) approach

This exploratory qualitative study used a community-based participatory research (CBPR) approach. This is an approach whereby researchers and stakeholders form equitable partnerships and co-construct research for the mutual and complementary goals of community health improvement and knowledge production. The co-creation of knowledge by engaging relevant stakeholders about a health issue leads to more meaningful research outcomes for patients, care providers, and communities [58,59].

The approach had interconnected stages (see Figure 2 below) to engage key stakeholders (people in the community; VCSE organisations; HSC staff; those working in Government and academia) throughout the process. The stakeholders played a fundamental role in co-constructing the research process and shaped the research development, design, sample, research questions, analysis, reporting and recommendations.

The research steering group and TMSNI Awareness Raising Working Group (ARWG) supported and informed the research. The research steering group, co-ordinated by CDHN, had oversight for the management and coordination of the study. It was a cross-sectoral group with representatives from the community, VCSE sector, health and social care, government, and academia. The group met six times throughout the duration of the project.

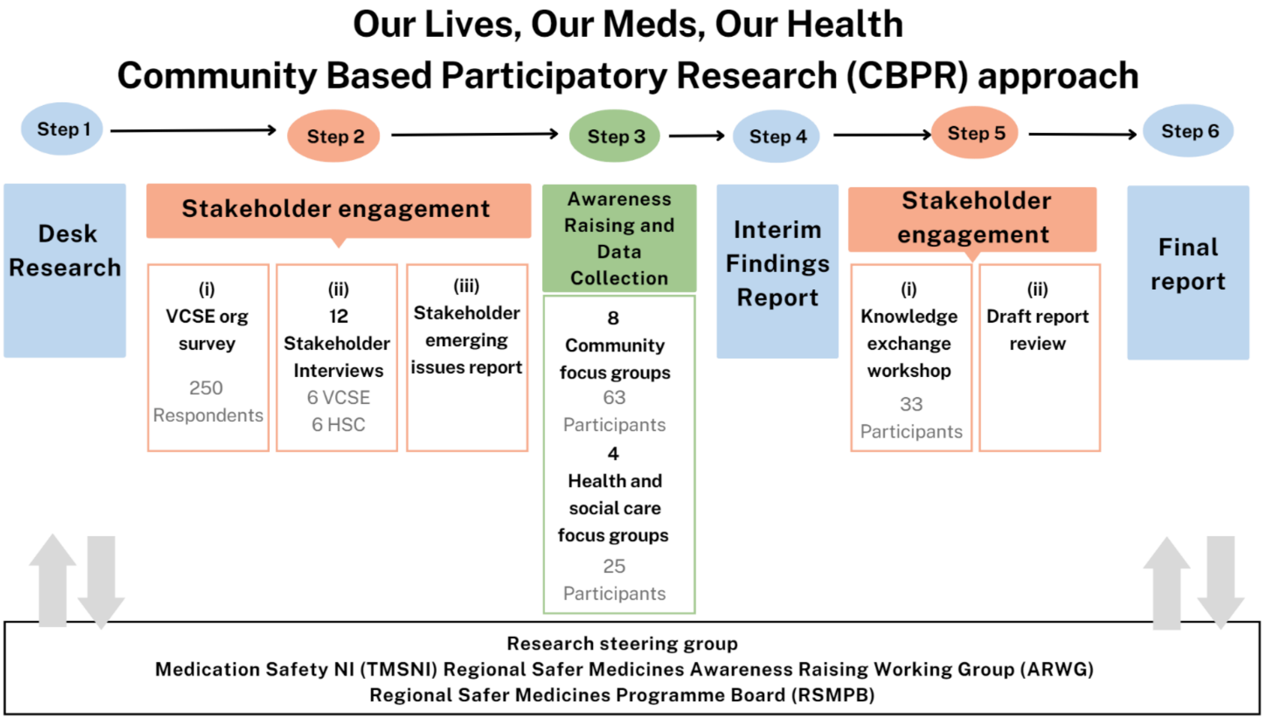


Figure 2: Our Lives Our Meds, Our Health Community Based Participatory Research (CBPR) approach

An overview of the methodology is as follows:

Step 1: Desk research

The literature review gathered existing evidence on SDOH and medication-related harm which helped to inform the stakeholder engagement (Step 2) and the sample and topic guides for the focus groups (Step 3).

Step 2: Stakeholder Engagement (Pre-data collection) - Development and design

A key part of the CBPR approach is community stakeholder engagement and involvement. This step enabled the research team to gather community-specific insight that was beyond their knowledge and:

- further scoped out the topic.
- raised awareness and assessed the understanding of medication safety and SDOH in communities.
- gained support for the work.
- developed the methodology by helping to
  - identify the focus group sample.
  - identify community organisations to work collaboratively with the research team to promote the research, host a focus group and find participants in their community to participate in the focus group.
  - developed the research questions and topic guides for the focus groups

This step of stakeholder engagement had three components:

(i) Voluntary, community and social enterprise (VCSE) survey

This short (5-minute) online survey explored the VCSE sector's awareness and knowledge of medication safety-related issues in their communities. Through the survey, participants could also register their interest in getting involved in other stages of the research process including participating in a stakeholder interview and hosting a focus group. The survey was promoted through CDHN contacts. It had 250 respondents from across NI.

(ii) Stakeholder Interviews

The stakeholder interviews aimed to scope out further the topic of medication safety with key leaders in the community and voluntary sector and in health and social care. Interview questions were framed around the topics included in the research objectives (SDOH, reporting medication errors, making decisions about medication), target groups in communities, and participant recruitment options. In total, 12 stakeholder interviews were conducted; one with a person in the community, 5 with people working in the VCSE sector, and 6 people with a background in Health & Social Care (2 of which also worked in academia).

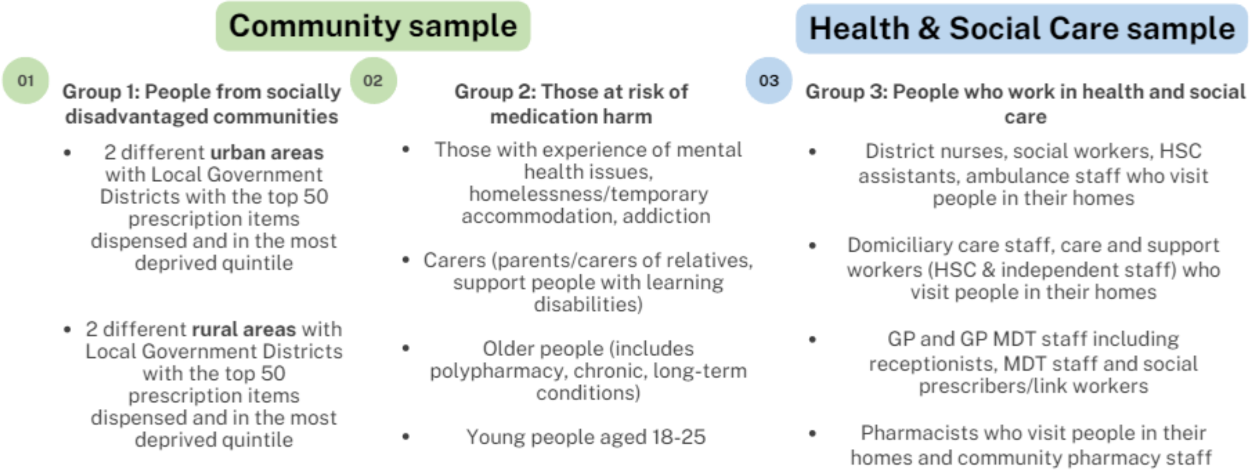
(iii) Stakeholder Emerging Issues Report

An Emerging Issues Report with the findings from the survey (i) and stakeholder interviews (ii) was produced and shared with those who took part and with the research steering group. This report, the literature review, and guidance from the research steering group informed the focus group sample and topic guides and helped identify potential focus group hosts and participants. If you wish to see this report, please get in touch with CDHN.

Stage 3: Awareness raising and data collection: Focus groups

Sample

Non-probability sampling techniques were used (purposive and snowball), whereby samples were determined with the research team's and steering group's expertise. The aim was not to test a hypothesis about the whole Northern Ireland population but to develop an initial understanding of the under-researched area of social determinants of health and medication safety. Figure 3 below shows the three target sample groups set out in the research objectives. Under these, four specific subgroups were then identified.



Community sample

01 **Group 1: People from socially disadvantaged communities**

- 2 different **urban areas** with Local Government Districts with the top 50 prescription items dispensed and in the most deprived quintile
- 2 different **rural areas** with Local Government Districts with the top 50 prescription items dispensed and in the most deprived quintile

02 **Group 2: Those at risk of medication harm**

- Those with experience of mental health issues, homelessness/temporary accommodation, addiction
- Carers (parents/carers of relatives, support people with learning disabilities)
- Older people (includes polypharmacy, chronic, long-term conditions)
- Young people aged 18-25

Health & Social Care sample

03 **Group 3: People who work in health and social care**

- District nurses, social workers, HSC assistants, ambulance staff who visit people in their homes
- Domiciliary care staff, care and support workers (HSC & independent staff) who visit people in their homes
- GP and GP MDT staff including receptionists, MDT staff and social prescribers/link workers
- Pharmacists who visit people in their homes and community pharmacy staff

Figure 3: Sample target groups

Community sample recruitment (Groups 1 and 2)

Community and voluntary organisations (identified through stakeholder engagement and CDHN contacts) were approached by CDHN and asked to host a face-to-face focus group and promote the focus group to the people in their community. Potential participants could register their interest with the host organisation or contact the research team directly.

HSC sample recruitment (Group 3)

HSC staff participants were recruited through survey respondents, stakeholder interviewees, research steering group members, ARWG members, Health and Social Care Trust (HSCT) Local Collaborators and CDHN contacts. The focus groups were also advertised on CDHN social media (Twitter, Facebook, and LinkedIn). HSC staff who wished to take part self-selected themselves, and all focus groups with this target group were held online via Zoom.

Focus group delivery

Participants took part in _one_ focus group lasting between 1 hour to 1 hour 30 mins between June 2022 and September 2022. The focus group sessions began with an awareness raising session which set the context for the research, why medication safety is an issue and introduced the Know, Check, Ask medication safety campaign. Providing this session enabled participants to be more engaged in the discussion and elicit thinking about their lived experience of medication safety issues. Many were unaware of the statistics and information on medication safety issues and the SDOH before the session. Two flexible discussion topic guides were used: one for community participants (Group 1 and Group 2) and one for HSC participants (Group 3). All participants received £10 cash or a shopping voucher for taking part. All focus groups were audio recorded for transcription purposes only.

Stage 4: Interim Report

Focus group audio recordings were sent to an external transcription service, and the research team analysed the transcripts using thematic analysis. The findings of the focus groups were presented in an interim report and shared with the research steering group and ARWG members.

Stage 5: Stakeholder Engagement (Post-data collection) - Analysis and Reporting

This part of the stakeholder engagement occurred after the data collection. It enabled stakeholders to analyse the findings and report writing process.

(i) Knowledge Exchange Workshop (KEW)

This 2.5-hour workshop brought together research participants, people from the community, community and voluntary sector staff, HSC staff and DoH staff (33 participants) to read and interpret the interim findings from the focus groups and shape the recommendations included in the final report.

(ii) Draft report review

The research team assessed what was discussed at the Knowledge Exchange Workshop and wrote a draft report including a conclusion and recommendations. This was shared with the KEW participants, research steering group and research participants for review and feedback before this final report was published.

Step 6: Final Report

This final report was produced to discuss the research rationale, methodology, and findings to provide recommendations for the implementation of the TMSNI plan.

Ethical considerations

A research governance review is required to conduct research with HSC staff whom the HSCTs employ in NI. Local approval, also known as Capacity and Capability, was sought for the focus groups and granted by each Trust involved (Northern HSCT, Southern HSCT, South Eastern HSCT, and Western HSCT) [*]. This approval involved identifying a Local Collaborator in each Trust as a point of contact in HSC who helped recruit staff.

Research governance only requires ethical approval for people in the community that are recruited through health and social care records. Therefore, ethical approval was not needed for this study to recruit community participants. The research team are members of the Social Research Association. Throughout the study, Research Ethics Guidance[iv] was followed.

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[*] Those employed by the Belfast HSCT were not recruited as a Local Collaborator could not be identified due to the wide remit of the area. Those working in the geographical area of Belfast HSCT that were not employed by the Trust were still eligible to take part.

[iv] Social Research Association (2021) Research Ethics Guidance https://the-sra.org.uk/common/Uploaded%20files/Resources/SRA%20Research%20Ethics%20guidance%202021.pdf

4. Findings

In this chapter, the findings from the focus groups are presented. An overview of the participant demographic characteristics is presented below.

Six key themes emerged from the thematic analysis of the focus group findings:

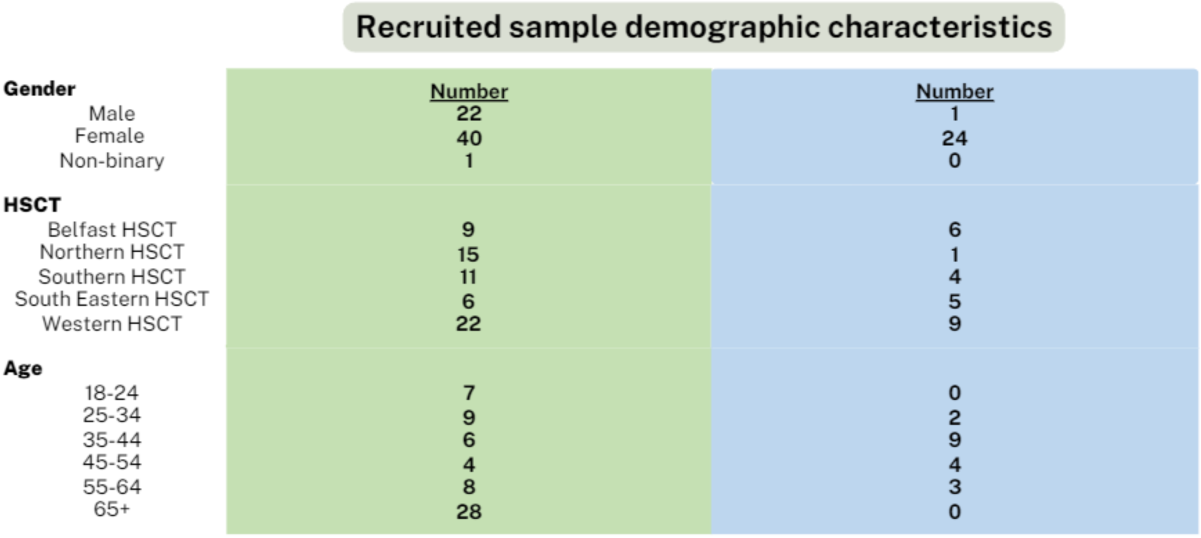
- Social Determinants of Health (SDOH)
- Health literacy
- Reporting issues and concerns about medication
- People being involved in decisions about medication
- Health and Social Care (HSC)
- Know, Check, Ask (KCA)

The quotes from the community participants and health and social care participants have been colour coded as follows[v]:

Quotes in green = community participants
Quotes in blue = HSC participants

4.1 Focus group participant demographic characteristics

In total, 88 people took part in the focus groups; 63 community participants across 8 focus groups and 25 people who work in health and social care across 4 focus groups. The demographic characteristics are presented in Figure 4 below:



Recruited sample demographic characteristics

	Number	Number
Gender		
Male	22	1
Female	40	24
Non-binary	1	0
HSCT		
Belfast HSCT	9	6
Northern HSCT	15	1
Southern HSCT	11	4
South Eastern HSCT	6	5
Western HSCT	22	9
Age		
18-24	7	0
25-34	9	2
35-44	6	9
45-54	4	4
55-64	8	3
65+	28	0

Figure 4: Sample demographics

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[v] Workshop and participant codes have been removed from all quotes to ensure anonymity.

4.2 Theme 1: Social Determinants of Health (SDOH)

Health is known to be affected by a broad range of factors, including the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These non-medical factors are called the Social Determinants of Health (SDOH)[60]. This section details the social factors that were found to impact medication safety.

4.2.1 Home life

Everyday life and routine

Everyday life stresses and strains can prevent people from taking their medication as prescribed and result in forgetfulness (unintentional non-adherence).

> *"Whenever you're* ***thinking about other things*** *it's hard to remember."*
>
> *"I take medication for an underactive thyroid and I'm off them now a week because* ***I forgot to order them*** *and every morning, I say oh, I must remember to order them."*

Having a routine appears to help people to remember to take their medication. However, people don't always follow a routine or may be away from home which can lead to errors.

> *"I take my morning ones [medication] with my breakfast and I take my evening ones with my evening meal, so* ***if ever I don't have breakfast or I don't have an evening meal*** *almost every time I've missed the medication".*
>
> *"If you're* ***anywhere else but at home*** *I don't take them because I forget".*

Routine was also noted by HSC participants, one described how important it was for routines to be **individualised to the person**, as their life circumstances will dictate their routine.

> *"One guy didn't get up until 3 in the afternoon, that was his morning medicines. I said…that's no problem, take them at three in the afternoon and then take your bedtime ones at two in the morning when you go to bed…he was taking it wrong because it said morning and this was afternoon and I said look, it doesn't matter,* ***that's your morning****".*
>
> *"Another patient,* ***I've got them moved them all [medications} to bedtime because she can't remember in the morning****, she's got the school run, she's got this, that, the next thing, the mornings are manic".*

Social life

One community participant described how when she was younger, she was careless with her medication as she was **socialising**,

> *"I wasn't always as good at taking all my preventers when I was younger because* ***I was out socialising, doing this, doing that****".*

Having a social life can also lead to people **forgetting** to take their medication,

> *" I went to a BBQ and my neighbour brought another bottle of wine and I'd already had one. So, I didn't take my night tablets that night just because* ***I was drunk****".*

However, people also do not take their medication to **relax/enjoy social events**,

> *"I haven't taken mine today because I thought right, this is the ideal situation of coming into [attending a focus group], I can't be trotting out there every half hour or whatever so I will take it when I go home but the rest of my day is screwed.* ***You do what you can for the circumstances you're in... otherwise you'd be trotting to the loo****".*
>
> *"So, people going to a wedding or going out for the day they* ***won't take their tablets because they won't be able to take a drink****...they'd not take their tablets because they'll think that [drinking] wouldn't agree with their tablets".*

HSC participants were also aware of this,

> *"Often it doesn't fit in with their lifestyle, they've got three times a day medicines,* ***they always go out and meet their friend for coffee so they never take the lunchtime one****, or it's the horrible water tablet and they don't want to take it because they're going out for coffee...so they just miss it and that causes problems".*

Prioritising others' needs

Having **caring responsibilities** may mean that people **forget to take their own** medication.

> *"I was really afraid actually with Calpol with my first [child], I never had children about the house so when I was giving Calpol I was making sure the dose, and everything was right, but I* ***forgot my own antibiotic for the next day****."*
>
> *"My mum has dementia so my dad sorts out her tablets but yet he has high blood pressure, and he had a mini stroke as well and* ***he tends to forget his, but he always makes sure she has hers morning and night****."*
>
> *"My father had a fall and was in the hospital...* ***if I was staying over at night [at hospital], I would remember when I'm over there, I should have brought my medication.*** *I take ten tablets at night and then I take three in the morning, I was going home about twelve o'clock because I didn't want to leave the hospital in case something happened, so I was taking all those tablets at once. It's a wonder I wasn't flying round the place."*

And as a result, people can **intentionally** not take their medication.

> *"I purposely don't take Amitriptyline on the nights I stay over in my granny's because* ***I know it makes me tired and I have to be able to stay awake*** *because I have to be able to hear if she gets out of bed."*

Bereavement

Going through a bereavement is a time when people may **forget** to take their medication or **do not prioritise their own health.**

> *"I had two bereavements within a short time, and* ***I didn't take anything for about a year, I wasn't functioning properly and even getting out of bed was hard enough****...so I never took any medication for nearly a year, just your mind doesn't function, you just go through day to day and you're living in a wee world".*

And also, a time when people **share medication** to help others through the process.

> *"When my husband died, of course **my kids they gave me this wee tablet that night** and I didn't know what I was taking".*

Domestic violence

Participants described how people's access to their medication can be **restricted** if they are in an abusive relationship.

> *"I think domestic violence is a big issue when it comes to taking medication. I've been there so I know what it is…**you're denied access to your drugs because you're too frightened to go in the house** or if your partner is there, you're absolutely terrified… experiencing that and knowing I should be taking drugs for TB at the time, it was horrific".*

Working patterns

One of the HSC participants commented that unusual work patterns can mean it is **difficult to access healthcare** and get medication reviews.

> *"If they're on drugs like preventative drugs for heart attacks and strokes it really matters to them but **it's actually quite hard to get them to recognise that and physically come in,** particularly lorry drivers… they find it incredibly difficult to engage with health services, because we all run Monday to Friday 8.30 am to 6 pm and sure if they're doing international runs to the continent sure they're only home maybe for a Sunday and then away again"*

4.2.2 Social support

Living alone

Community participants described how **living alone** can impact medication safety as they do not have someone to remind them to take their medication or check they are taking it properly.

> *"I have to look after my own [medication] cause by the time, when they [family] come down to see me it's the middle of the day**… I have to depend on my own mind all the time**"*

This was also a concern for HSC staff.

> *"Whenever we see patients leaving the pharmacy with a big bag of medicines and **you think to yourself how they ever manage that**, particularly if they're on their own, even simply remembering how to take the medicines at the right time"?*

People in the community were also concerned that those living alone do not have anyone to **watch for adverse reactions**. One participant described her own experience of this.

> *"I had blood pressure tablets that I was allergic to, and they made all my joints lock, and I couldn't speak or anything and **I was left in the house on my own for days**, **I couldn't do anything**."*

Someone to collect and organise medication

People described needing the social support from family or friends to **collect and deliver medication**

> *"Like the social factors, definitely for older people or people who do have limited ability, like she's [participants mother]* ***not able to go and get her script, we have to go and pick it up."***

And someone to **organise** their medication.

> *"It's her age, she's 97, she tells me – I know everything I'm taking but she doesn't. Oh my god, it's like…****she's got like a hoarder's house she lives in, so everything is in chaos****".*

This was also discussed by HSC participants.

> *"I would say family support has a big impact…* ***family is busy, they don't live near them and by the time they get there there's a delay on the time****, they mightn't get the prescription lifted from either the GP surgery or from the chemist and that's a delay in the patient getting their medication initially".*
>
> *"A lot of the time I think they have difficulty maybe getting it organised, so* ***some people may be on 8 or 10 different tablets, loads of different types of boxes, they might not always have someone that organises it for them*** *so they just kind of take them randomly I would find. Or they have multiple tablets and they're maybe taking old tablets and some new tablets".*

Someone to check medication is being taken correctly

People in the community described how they often have to check that their relatives are taking their medication correctly.

> *"My grandmother had to take medications, she's 92 God bless her and with Covid and the lockdown and not seeing anybody, she forgot to do it and she had those eyedrops and stuff like that,* ***we were trying to sneak in when she wasn't getting it*** *because she was living in a fold at the top of the town, and she doesn't have carers."*
>
> *"You should see my mum and dad, I say how do you know what you're meant to take when…they have had all their medicines reviewed because* ***me and the sister has kind of stayed on top of it*** *and they have their yearly reviews but still because they do forget it and life does get busy."*

In the focus group with **young people aged 18-25**, they all agreed that they got support from family members and **taking medication is not something they would normally do without help**.

The **importance of social support** in medication safety was also noted by HSC staff.

> *"If there's a family member also stepping in, they can see or they pick up the script every week,* ***they can see that certain medicines are not being given*** *or maybe the night-time ones are not being given."*
>
> *"I'll always ask them [the people I support] how they manage their medication and* ***a lot of them would say oh, I would be lost without my daughter,*** *or I wouldn't be able to manage*

> *my medication without my son. But a lot of our participants live alone, and they don't have that family support network. So, a lot of them would rely on their family network."*

Challenges in providing support

Family support was recognised as incredibly helpful in medication safety by both community participants and HSC, however community participants described times that they and their family members had made **errors** with other people's medication.

Some community participants described their parents supporting each other with their medication and not giving it to each other correctly:

> "*My dad said she [mummy] was sick and had a bug and* ***he [Dad] stopped giving her all the medication*** *and he was like nah, she's sick.*"

Others described medication errors occurring due to their **busy lives.**

> *"I know myself with my son's afternoon tablet at three o'clock…I go to get the medication at three o'clock then notice oh god, this strip is empty, it's gone, and I've not repackaged it into my handbag again and maybe the other child has got another appointment at four o'clock and then* ***by that time it's too late to give it****…it impacts your whole house."*

Some participants were parents of children with **autism and sensory issues** and described how the everyday management of their condition can mean medication is missed.

> *"And it's all the sensory issues in the morning too getting them dressed, so* ***by the time you've got them dressed you're stressed out*** *and you come downstairs, and* ***you've maybe forgotten to give the tablet or else they dig their heels in*** *and they're not going to take it."*

Community participants who were on medication themselves spoke about how it was so important to remember to take their own medication, so that they could help those they care for with theirs

> *"If you've forgotten to take your own [medication]* ***it's even more stressful trying to give somebody else theirs****".*

In the HSC focus groups, a participant described a family member making errors due to miscommunication.

> *"We've had a family member make an error. He only got medication in the morning but since he moved into their house there was an increase…* ***the next of kin didn't understand****…He signed out the tablets, it was explained to him about the increase, but he was forgetful, and he just gave the morning medication".*

Medication refusal

Community participants described instances when their family members refused to take their medication as prescribed,

> "*Sometimes arguing with them [your parents] too because* ***they don't want to be parented as they're your parents*** *is kind of a battle, trying to get them to see reason sometimes*".

And instances when caring for those with additional needs refused medication,

> *"Mine is a teenager with pathological demand avoidance, she* ***refuses to take tablets because of the demand avoidance even though she knows she needs them****, and* ***she wants to feel better but it's that can't/won't.*** *She won't take them, she can't take them, but she wants them, and she needs them and she wants to feel okay, so her mental health would decline a lot…I mean she takes fits and starts at it but I mean that's again, that's something that you can't control because again, she's her own person too."*

A community participant described how their ex-wife would pretend to take their medication when carers were in their home,

> *"I had carers come in for the ex-wife but I was the main carer of her for 20 years…they were in charge of giving her medication…I knew she's messing about with this medication so I stood one day at the hall door where I could see the carer coming in…popped both the blister pack and put the medication on the table and I stood and watched and she [ex-wife] just put them under the table. "*

4.2.3 Where you live

Social stigma

Community participants described the **social stigma** in their communities attached to taking medication.

> *"I think the social status around mental health or pain management, you're* ***constantly judged****. I remember one time they'd given me this and this, I had surgery on my back, and they were like* ***'but why are they giving you a script for diazepam, is that not for old people?'*** *So, you have the social opinions of everybody else."*
>
> *"I remember being in school and* ***if you had to take painkillers in school it was like you were weak,*** *you couldn't handle pain so you just wouldn't, you'd just suffer the pain because you didn't want to appear as a weak person or whatever. It was like you were scared to take it because you didn't want to be criticised for not taking pain."*

And **in their own families**

> *"I think a lot of I has to do with the way you're brought up with regards your attitude to tablets and stuff…my dad was, he didn't really want us ever to take tablets and that's still in my mind…I would be really bad before I would want to take anything else. P2: I'd be the same. A lot of my family – why are you taking them?"*

Another described living in a small community and not wanting the **people in the pharmacy to know** what medication they are taking.

> *"I think depending on the pharmacy that you get as well, some of the staff are great and sometimes you nearly don't go in on certain days because you know somebody is going to be working and it's a small town and I don't need them to know what medication I'm on.* ***I don't want them to be like – oh she's on that, what's she on that for?"***

Support in the community

Community participants spoke about being referred to **support groups** in the community and how the support helped them with conditions, medication, and shame and stigma.

> *"I think people feel very isolated because you're afraid of shame and stigma and the only way to crack that is to have a* ***support network that is non-judgy, non-biased*** *that will come in and say right, what support do you need, how can I help you.* ***Not oh, you've done this wrong…****because I think with mums with kids anyway regardless of if you have mental health issues or not you feel judged by society on everything you do."*
>
> *"I just took myself back off them [medication] and it was the social stigma of having to take anything and I was like, I'm not telling people. I'm coming here [support group] two years and* ***for the first year my daddy thought I worked here, I was just not telling people,*** *I refused to talk about it, like I really did."*

People felt that more support in the community may mean **less medication.**

> *"It did take a couple of months and by the time they were giving me the therapy or giving me someone to talk to I literally corrected it myself* ***by coming to these [support in the community] groups*** *or by offloading onto very close friends that mind what was going on and kind of building myself back up as opposed to waiting."*
>
> *"If there was more upstream support in the community for alternatives to medication, if there were services there, if there were support systems there… Then so many more individuals, people, members of the public, vulnerable adults, children* ***wouldn't end up on medication."***

Community you live in

One of the community participants described the high level of prescription medication misuse in his community.   He was aware that prescription medication was being sold on the black market in his local shop and that the local pharmacist had to put measures in place to try and curb the issue.

> ***"I lived in an area that was really bad for drugs and selling the drugs*** *and I'd sign my prescription whenever I lifted it to say I lifted a pack of 28 of pregabalin and a pack of whatever tramadol and then whenever I came back to get the script whenever it would have been finished I'd have signed or if I didn't finish the pack I would have to bring the pack in because* ***our local shop used to sell them.****"*

Physical isolation/rural isolation

Some rural communities don't have pharmacies or delivery services near them to access their medication.

> *"Isolation. Physical isolation/rural isolation can be very difficult for people who* ***aren't close to the services*** *to facilitate them getting it."*

4.2.4: Income

Everyone in NI is entitled to free prescriptions, therefore are no direct financial barriers to accessing prescribed medication. However, in focus group discussions, conversations arose around the cost of living and poverty and the indirect impact that this can have on medicine safety.

Transport

People not having enough money for **transport** to collect prescriptions or to go to HSC appointments was identified by community and HSC participants as a factor that could impact medication safety.

> *"I know a lot of pharmacies now are doing delivery but it's at a charge and **obviously with the cost of living** and the petrol they don't mind that but then again, not everybody is going to be able to afford that."*

> *"**Poverty**. Not having the money to go to the chemist is a big one. I would see people all the time who maybe **don't drive, don't have the bus fare,** I didn't pick it up this week but **when I get my money on Friday I'll go then,** by which time they've missed a few days medication or as compliant with it as the GP would like."*

This can result in medication being **taken incorrectly**,

> *"Maybe won't collect their prescriptions for weeks at a time, when they eventually get down, then **their medication is all out of sync** because they're not taking it regularly."*

And some people can feel **embarrassed to ask** for a delivery.

> *"Some people are a bit embarrassed to ask for a delivery because they're not elderly, **they don't see themselves as unwell** and they often go quite a long time without actually picking up their prescriptions."*

Medication and eligibility for social welfare/security payments

In the community focus groups, there was a perception that people get prescriptions for certain medications as it helps with their Personal Independent Payment **(PIP) assessment**.

> *"There is probably a wild lot of wastage of tablets because I know ones I actually talk to and I say well, if you don't need them tablets why are you ordering them. And know what they actually turned round and said – because the **PIP checks with my doctor that I'm taking my tablets**."*
>
> *"People do just take the medication for PIP, **especially here [area of deprivation]**, we probably have the highest rate of DLA and PIP."*

HSC were also aware of this perception.

> *"It probably is the 1% where there's harm generated and there's a secondary gain in the background, they're wanting to get that **additional disability allowance.**"*

In the community and HSC focus groups, participants raised people **selling** their medication for extra income. In one group participants spoke of how they were aware of prescription drugs being sold.

> *"Maybe talking about social deprivation, maybe they're getting medication and they're selling it. I've come across that, people that have been prescribed medication or people saying to me, **I'm getting a few tablets from such and such down the road.**"*

4.2.5: Physical and Psychological Capabilities

In both the community and HSC focus groups, discussions were raised about people's physical and psychological capabilities to take medication as prescribed, and the need for additional support to do so safely. In this context physical capabilities refers to having the physical strength, skill or stamina, and psychological capabilities refers to the capacity to engage in necessary thought processes – comprehension, reading etc[vi]. While many issues were raised in terms of older people, these issues applied to people of all ages and those who have disabilities/difficulties/impairments.

Physical Capabilities

Many of the participants described the issues older people have in **opening** medication packets and jars.

> *"I have found that a lot of them [older people] are on medication which they really do need but they don't bother taking it because they* ***can't undo the box or the bottle****... They really do struggle."*
>
> *"My granny takes patches for pain and patches for dementia, if somebody else is there she can get them put on, that* ***she herself wouldn't be able to cut them out of the packet****, open them out of the strip, unpeel it."*

One of the HSC participants described how a patient couldn't accurately measure medication post-stroke.

> *"They were having issues with a particular product they'd been given and actually* ***accurately measuring 3mls*** *and then being able to actually physically take it because of just physical disability post-stroke."*

Others described issues people have in **swallowing** medication.

> *"Swallowing is a big, big issue in older people."*
>
> *"Some people just say ah too many,* ***I can't take that many****, they may have swallowing difficulties or other complications."*

Participants described the challenges associated with having a **hearing** impairment and ordering medications.

> *"When I take my hearing aid out, I'm just deaf and when they phone sometimes, I don't really hear it and then you're listening for what they're saying...****I miss what they're saying*** *so I have to put the phone down and do it again, then sometimes I catch it."*

Psychological Capabilities

People with psychological incapabilities can find it difficult to manage medications.

[vi] As explained by the COM-B model (Capability, Opportunity, Motivation – Behaviour) for understanding behaviour[vi]

> *"And there are vulnerable adults in the community and for our people with learning disability, managing a medication complex and difficult (P1) …Especially if they have no one to help them with it." (P2)*

> "At the *moment I'm trying to synchronise medicines for a girl who has **slight learning disabilities**, her mother has had a stroke so she's not able to help her at all."*

And **may not pro-actively seek reviews** of their medication.

> *"I actually said to my husband yesterday, when are you due to get reviewed, he said, "they told me just to phone", well **he's autistic and he's never going to phone.**"*

As people get older, they can have **memory** issues and experience **confusion** with their medication.

> *"I suppose the thing we've talked about before is confusion and **you didn't realise you hadn't taken it.**"*

This is a particular issue with people with **dementia**. Community participants described experiences with their grandparents.

> *"My granny has dementia and I look after her and I go to her appointments but before that my granny would be **coming out with scripts and she doesn't even know what they were** for or what way she was meant to be taking it."*

This was also noted by HSC participants.

> *"We might have some clients that might have some episodes of confusion. So, although it states on the care plan that our staff may have to administer or supervise, we have found on occasions that the **clients have went and administered the medication themselves**, but they've not just administered one dose, they've maybe administered two."*

Domically care staff also described challenges in helping people with dementia to take their medication.

> *"They [clients with dementia] would be reluctant to take their medication from the care staff just because **they don't know them** and they're not familiar with them and they're maybe worried about what medication it is they're giving them."*

4.2.6: Mental health/addiction/homelessness

Mental health

Community participants described how poor mental health impacted their medication use. For some they were feeling **low or worthless** and didn't order or take their medication

> *"I know my mental health affects sometimes, I get my repeat prescription from the chemist and although they originally said it's 48 hours it's more like a week before you actually are running out and **if I'm feeling a bit low or I sometimes forget to ring them** and then I'll have to have like perhaps a weekend without the medication."*

> *“I have a neighbour who has mental health issues and having been there myself I’m quite sympathetic to her needs but she’s a person that would be prescribed something from the GP or the hospital as it has been on occasion, but she only takes a certain amount and then she stops taking them and then she* ***goes back to being what she was like before.****”*

Another participant described telling a doctor they were having trouble sleeping, to which they were prescribed sleeping tablets (instead of mental health support), which they used to attempt **suicide.**

> *"I did [take them correctly] for a couple of days and eventually I just said you know what,* ***there’s no point*** *and took the whole packet.”*

Another participant spoke of buying **over the counter medication to overdose** when they were feeling suicidal.

> *"I was buying Nurofen over the counter, and* ***I was going to different chemists all the time*** *because they would only sell me so much, I think it’s a box they’d serve you."*

Issues with mental health influencing unsafe medication practises were also noted by HSC participants.

> *“I’ve a few people who went in really low,* ***stopped taking their medication*** *and it just makes the situation worse.”*

Addiction

Participants described becoming addicted to medicines resulting in overdosing, and other addictions influencing people to forget to take their medication,

> *“I was prescribed antidepressants and diazepam and I didn’t take the diazepam correctly at all because my head was all over the place. And I probably did take many more than what I should have because I just found* ***they calmed me right down*** *and I kind of way almost got addicted to them.* ***I wanted that feeling.”***
>
> *“See I get fed up, I was an alcoholic so I would just* ***hit the drink*** *then. That’s me, I just forget about medication altogether then, just throw it to the side.”*

This was also highlighted in the HSC focus groups

> *“I’m working with a man who has a serious drink problem, and obviously when he is very inebriated, he* ***doesn’t remember to take his medication.****”*

A community participant highlighted issues with being prescribed medication which can become addictive,

> ***“[there is medication] that is the equivalent of taking two injections of heroin*** *but sure they hand it out to you willingly in A&E when you’re sitting with a broken arm. So, they really need to start taking a bit more accountability for their actions instead of blaming the people with the addictions because* ***they wouldn’t have addictions if they weren’t given it in the first place****."*

Homelessness

A HSC participant worked in a **homeless hostel** in a previous role and had many experiences when service users did not take their medication as prescribed due to their **mental health**,

> *"We had sixteen service users and **out of the sixteen I would say maybe two people took their tablets correctly** and the rest didn't, and it was because of their mental health... they weren't being informed right why they need these tablets and so, they wouldn't take them. And then **we would see their mental health obviously getting worse**"*

Issues accessing services due to addiction/past behaviours/homelessness

HSC participants gave examples of people in the community who are unable to access services as a result of their addictions, homelessness and previous behaviours.

Some people are **barred from the pharmacy.**

> *"I work in quite a small rural area, and I work in mental health there are a few of my clients that have been barred from the local pharmacy due to their behaviour. **Usually a bit dishonest, losing their scripts or telling a few lies** etc. Obviously, the pharmacists don't just bar them like that, this is **years and years of build-up…**how do you work that whenever they've got to go to another town, and they don't drive and they're alcohol dependent and they've no family and they're living in poverty."*

Some people are **unable to register with a GP** because of previous behaviours.

> *"I remember looking after a guy and I don't know whether he was discharged from his GP surgery because he'd **missed so many appointments**, so the problem with him was…he **couldn't get a prescription** because he didn't have a GP."*

Or due to being homeless.

> *"Because they were homeless the **doctors wouldn't register them**. So, they had nowhere to go. So, these people were just getting worse…there was **nobody there to help them.** We saw a lot of those people. **It ended quite badly for a lot of them** because they haven't been able to get the support to give them the right medication and help."*

Some **opioid (pain relieving drugs such as morphine, oxycodone) substitute services** were described as **not being available locally** and people have **no money to travel.**

> *"Whenever I worked in addictions a young fella who was in and out of prison and he was prescribed opiate substitute therapy (OST)…**none of the pharmacies [in his area] had space to administer this to him**. Obviously he had a bit of a colourful history and he couldn't be seen to walk through the streets, he had to go to [place name removed] and he wasn't safe to walk, to get a train so **most of the time he was trying to get taxis and he couldn't afford it** and going to [place name removed] six days a week was really mounting up, even if it was bus fares. So, really his cycle was he used to come off his OST just due to the logistics of collecting it and would have then **resumed use and mostly ended up back in prison again.**"*

4.2.7: Access to health care

Appointments

Some community participants shared experiences of being pleased with the care they received with previous GP appointments.

> *"Our doctors' surgery, I'm really lucky, he phoned back the next morning and… I sent him a photograph and my **medication was ready that afternoon** and it cleared up within 2 or 3 days… and whenever I was bad last year… I was so ill, and my doctor called on the way home."*
>
> *"My mummy's doctor phoned me at nine o'clock at night because she can't always hear on the phone, so he'd ring me to have a conversation with mummy's permission… She was working his way through paper. He's **not sitting there twiddling his thumbs like people seem to think they are**, they're not."*

However, a common issued raised in all the focus groups was difficulty in **getting a GP appointment**,

> *"It's such a big deal to get an appointment with the doctor you **lose interest in it.**"*

> *"I started 8.20 am in the morning ringing and by the time you get through it's around 9-ish or maybe 10 and they'll say oh, the **appointments are all taken for today** unless it's an emergency."*

Without appointments, people **can't discuss** their medication.

> *"It's very hard to get a doctor nowadays… it's not their fault, there are shortages. But do you see for us taking the tablets and being on them for a length of time **how do we know**… you can cut it down for our health without damaging your health by cutting down. **There's no guidelines**"… You're continuing, you're just **hoping for the best.**"*

HSC participants echoed this difficulty with their clients' experiences,

> *"They're [clients] like, Awk no, I'm not phoning the doctor, sure you're on the phone for an hour… So, a lot of people, although you might advise them…they don't want to because the **process to get to the actual doctor is too long**, so they just don't do it."*

Some community participants were also dissatisfied that the **limited time** in appointments, and the **'one appointment one issue'** policy in some GP practices means they don't get an opportunity to discuss their medication.

> *"There's some of them **wouldn't give you time to kind of talk**, you're in the door and straight out the door again for the next one to come in."*
>
> *"I was in with a doctor, and I was saying….and then I went to say something else – **oh I'm sorry, only one thing!** … "You can't say two things, you have to make more appointments."*

Participants also acknowledged that GPs do not have the time to give longer appointments.

> *"I went to my GP the other day and the person that was in before me was there for half an hour and then she took half an hour with me in her ten-minute appointments, so **her room was sitting completely full**, she didn't get a lunch break that day."*

And that with **multiple healthcare professionals** involved in care, it is difficult to keep on top of all the effects of medication.

> ***"****I suppose that's part of the problem when you have a number of conditions and you're being looked after by a number of professionals who is the one person that **takes ownership** to make sure that none of these medications have a detrimental effect on the others that you're on. You could say well yes, it's the GP but we know that GPs, number one, they don't have the same level of expertise that these consultants or specialists would have, and they're **overworked.**"*

Some community participants voiced feeling uncomfortable telling **receptionists** their health concerns.

> *"Sometimes you'd phone to make a doctor's appointment or whatever and the receptionist will say what's wrong with you… sometimes it's a very personal thing and you don't want to say. Why are they making all these questions, they're not doctors. I think there's some things that I would not tell a receptionist."*

GP Practice Multi-Disciplinary Teams (MDT)

Community participants who use an MDT GP practice spoke positively about the additional HSC services offered by a **practice-based pharmacist** that can help with medication safety.

> *"Luckily now we have a pharmacist in the health centre where all the doctors are and he has **much more information** for he has immediate access to the doctor whereas my own pharmacist said well, I have to ring the doctor to see."*

The benefits of MDTs were also highlighted by HSC participants.

> *"We do have a pharmacist regularly there [in the practice] and they are **regularly ringing and reviewing** medications and all of the scripts and repeat prescriptions etc. and keeping a close eye… a lot of polypharmacy going… and stopping over-prescribing."*
>
> *"We have a pharmacist in our MDT team, so **if I was a bit concerned, I'd speak to the pharmacist** and ask them to maybe contact the patient and do a review with them to see if maybe we can look at their situation."*

Community pharmacy

Many community participants **spoke highly** of community pharmacy, their knowledge and expertise and the ease of access of advice and guidance on medication.

> *"Another **pocket of unsung heroes** I think are the pharmacists (P1) …They're very underrated (P2) And their knowledge … People don't understand the amount of training they actually have to do (P1)."*
>
> *"I go to the same chemist all the time and one day I had a cough and the wee girl was going to give me something and the chemist came down and said no, you're on such and such tablet, he said because you have paracetamol and you don't want to mix with that, so I said to myself*

> *after that just keep going to the same chemist because they **know you and keep an eye on you.**"*

Prescriptions

Some participants in the community found the process of ordering medication difficult.

> *"There's **got to be an easier way** to get it ordered every month without having it written down in three or four different places and setting alarms. "*

Difficulties ordering medication has led to people ordering online. One participant had cut down their medication and then when they needed it again, they couldn't get it as it wasn't included on a repeat prescription.

> *"I said well, can I speak to the doctor, they said no, you can't. So, then I bought them myself online until eventually I spoke to the doctor, and they did give me them then and she said, why didn't you get them, and I just said, well the receptionist said no. **There was a lapse** in it."*

And it's not clear that all orders are not repeat prescriptions.

> *"Some medications they don't put on the repeat. (P1) ...But **I didn't know that!** (P2) ...Nobody told you. (P3) ...Nobody told me that's the way that worked online, I just thought because it wasn't on there that I wasn't to be using it anymore and that's the way it was (P1)."*

This was echoed by HSC participants - one described their personal experiences.

> *"It wasn't until my mother got too frail, she's 92, to order her own medicines and I had to start doing it for her that I realised just what **a head melt ordering medicines** was."*

Blister packs

Blister packs[vii] were raised frequently in the focus groups, who was entitled to them, how do people get them and their advantages and disadvantages.

Many community participants saw the benefits of blister packs in improving medication safety.

> *"I'm pretty positive that she was taking medication that was **wrong for years,** that's why we got the blister packs because she would have just been taking it [wrong]."*
>
> *"**You can see the rationale**... certainly for long-term medication with an older person with the list of issues that you said there, mental health issues or elderly or confused or whatever, you know, you can see the rationale."*

However, there was recognition that blister packs don't solve all problems relating to medication safety, as community participants commented they still got **confused.**

> *"I have a blister pack and some days I could take the **wrong days** to start with or else I took the night-time medication in the morning."*

[vii] Blister packs, sometimes called monitored dosage systems, multi-compartment compliance aids, dossette boxes or trays are a sealed medication management solution which have separate compartments for days of the week and times of the day and can assist people with taking their medications.

This confusion was echoed by HSC participants.

> *"Like everybody is only human and blister packs can be confusing. The calls [times to administer medication], like the morning, lunch and tea and bed calls can **all look the same.**"*

Blister packs were described as potentially **unsuitable** for some people.

> *"I have one lady that has a blister pack chock full and said **could you swallow all that**? And she had a point, and so, rather than picking and choosing she just didn't take anything."*

And that they don't always address stockpiling

> *"I went in last week and removed six medi boxes because everybody thinks medi boxes solves the problem, so I removed six medi boxes completely untouched."*

Some HSC participants also discussed the **difficulty in obtaining blister packs** and the impact that waiting can have on medication safety.

> *"It is hard to get blister packs for patients…somebody would need a blister pack but there's waiting lists in a lot of pharmacies for that, so that has an impact as well of why medications **aren't taken on time.**"*
>
> *"I would just second that in my area as well, the blister packs are almost really hard to get… part of what they want for services for the carers to do, they need to have a blister pack in place otherwise they **won't administer** the medication."*
>
> **"***Whenever you go out to do like an assessment or a review you kind of be trying to organise the blister pack but then you can't get the blister pack and you're **relying very heavily on*** **family.***"*

However, in some areas there are no issues getting blister packs.

> *"In my area, blister packs are **not really a problem**, I think there was a wee while there where some of the pharmacies weren't getting paid for having this service but now that has been resolved in my area and we don't have a problem, even though we are a rural area."*

Summary: Social Determinants of Health

People both intentionally (making an active decision) and unintentionally (forgetting or due to circumstances out of their control) did not take their medication as prescribed.

Social factors found to impact medication safety:

- Busy lives – being out of routine/socialising/unusual working patterns.
- Caring for and prioritising others' needs.
- Bereavement and domestic violence.
- Living alone and having limited social support.
- Social stigma attached to some medication.
- Prescription drug misuse and black market for prescription drugs.
- Perception that certain medication can help in Personal Independent Payment (PIP) assessments.
- Rural and physical isolation.
- Access to transport.
- Varied physical capabilities including difficulty opening medication/measuring doses/swallowing tablets/ordering medication.
- Varied psychological capabilities including difficulty managing/remembering medication/confusion.
- Poor mental health, addiction, and trauma – the addictive nature of some prescription medication not always being considered by healthcare professionals.
- Difficulty accessing medical appointments and limited time during appointments to discuss medication.
- Difficulty ordering prescriptions.
- Difficulty accessing public services due to homelessness, addictions, or previous behaviour.

Additional points:

- Community groups were identified as being helpful for addressing shame and stigma around medication.
- The benefits of blister packs to support people with medicines adherence were identified. However, it was recognised that they do not always address medication safety issues.
- Health and social care staff were aware of social factors that impact on medication safety, however community participants voiced that these were not always considered in their care.

4.3 Theme 2: Health Literacy

Health literacy is a social determinant of health. Specific questions about health literacy were not asked in the focus groups, however, it emerged as a dominant theme in the findings and as such the research team felt it warranted its own section in the report. This section presents experiences of people accessing, receiving, and understanding instructions, advice and guidance about their medication.

4.3.1: Knowledge and understanding of medication

Some community participants had a **good knowledge** of their medication.

> *"Basically, **I know** what I'm on and what they're for."*
>
> *That's one thing about me, if I'm on medication or the weans [children] are on medication I'll know **every little last detail** about it to know why I need to be on it and the reasons why I need to be on it and the reasons why they need to be on it."*

And knew the **benefits** of taking it.

> *"I was taking anxiety tablets and stopped taking them because I thought I'd be able to manage otherwise with doing activities and all that, but it didn't work…once you get a situation…you fall back into it…The tablets **do help.**"*

However, many community participants were **unsure** about what their medication is and its **purpose:**

> *"**Half the medication I'm on I don't even know if I should be on it**, I've been on the medications so long."*
>
> *"Somebody just mentioned the statin, I'm on the statin and I'm **not sure why.**"*
>
> *"I have things there and a lot of it is to do with blood thinners, there are **fine lines** between those things so I can't remember actually why the doctor gave me that for blood… but it makes me run to the toilet."*

And the **danger** in taking other medications alongside prescribed medication,

> *"The tablets I buy out of the health shop, I was buying some of them to help me with my pain and I thought oh, these are great and then somebody said you **shouldn't be taking them** with them tablets but sure I didn't know."*

This experience was mirrored by the views of HSC staff,

> *"It's sometimes a real lack of understanding, **they don't understand what that tablet is doing for them**…maybe the statin is going to reduce their cardiovascular risk, reduce a stroke in the future perhaps."*
>
> *"But I suppose for me, for some of the elderly patients and the mostly elderly that we'd find this problem with is that they don't understand why they're on this new tablet and they may have a*

> *box of other tablets and they may think God, sure I'm* ***already on*** *a blood pressure tablet and* ***why do I need another one.****"*

And the confusion that can be caused by the **addition** of new medication,

> *"When an additional tablet is added in that it's really important that the patient understands that this is an additional tablet, that you* ***don't stop*** *what you're currently taking."*

Knowledge and understanding of medication safety

Some people in the community stated that they **always** take their medication as prescribed and **didn't comprehend** why others also didn't,

> *"I* ***take mine religiously*** *in the morning and night and my painkillers in between."*
>
> *"****Why would you not*** *take your tablets if they were prescribed to you... And if it didn't agree with you, why would you not ring up and say and get something else then."*

And gave examples of **techniques** they use to take medication safely,

> *"I realise that I miss one because these days fortunately there's a sort of sequence in the foil so you can see you didn't take one and I suppose most of the time I would* ***just check the information*** *with the tablet and see if it's a case of taking any and waiting now or don't double dose because you've missed it for a whole day."*

People do not always realise the **impact** of not taking their medication as prescribed / not following the instructions.

> *"Foolishly I stopped them so perhaps if I stayed on them* ***this might not have happened****...that was my choice...I think I have a bit of blame in that and I also think the GP has a bit of blame in that as well because it wasn't really enforced."*
>
> *"It happens with antibiotics as well; you're prescribed it for seven days and you get the* ***feel-good factor*** *kicking at about day 5 and you end up with something like MRSA."*
>
> *"People don't see it as a dangerous thing if they take their medicine a wee bit* ***later*** *or oh, I've forgotten it, I'll take it the next day. You* ***don't realise*** *there's a knock-on effect to doing that."*

This was echoed by HSC participants,

> *"I* ***don't think they realise****...I say you do realise you shouldn't be doing that or you're really overdosing, you're putting your liver under quite the strain... whenever they realise...– oh, I* ***didn't know*** *that. So, it's that sort of lack of understanding, it's not that they necessarily do it intentionally."*
>
> *"In the homeless hostel [participant worked in]... we used to keep the medication, he was coming every day collecting it, and it wasn't until we got a feeling there that there was* ***something not right*** *and we did a room search and we found all his medication* ***in a cupboard****...it was actually epilepsy tablets and we asked him why he wasn't taking it and he said it* ***wasn't helping****, and about a week later he ended up taking his first fit in about five years because he wasn't taking his*

> *medication…We've had a lot of patients or service users just think, sure it's not doing anything anyway, just because it is actually doing what it's meant to be doing,"*

> *"The main ones I see that probably are the most dangerous ones I see would be with the blood thinning tablets where people sometimes don't realise how important it is to take the **evening dose**, I think they take it in the morning and that does them but it's so variable, that's the problem. And even you might be speaking to someone, and you might think ah yes, they have a fairly good understanding and then you ask them something and you realise they really don't."*

HSC participants commented some find it harder to understand the need to take **preventative** medicine.

> *"A lot of that possibly was information, we would kind of give them a bit of information and counselling but it's that **ongoing** that needs to be done, that reinforcing because they don't feel any different, they don't feel different so that's why I used to get told – well I **didn't feel any worse** when I didn't take it so what's the problem?"*
>
> *"Quite often you will find they'll take **symptomatic treatments**…because they get heart burn if they stop it but they're not taking…their statin or their blood pressure tablets. And so, you have to sort of drill down into that to find exactly what's going on there."*

4.3.2: Instructions, advice and guidance

Written information and instructions

Participants had mixed reactions to written instructions about medication, both in the form of leaflets inside prescription boxes and labels given by healthcare professionals.

Some participants **routinely** read the information/instructions that were given with their medication,

> *"I read everything."*

People had positive experiences from reading the written information provided, such as knowing **not to mix** certain medications,

> *"I don't take it anymore but it's still on my repeat list but now it's been established that I've had a mini-stroke and no intervention required but only I'm sensible and I went through any medication in the house and the tablet that's still on my repeat list which luckily I don't take it but if I had been taking it it's the wrong thing to take because it **warns do not take if** you've had a TIA."*

Some mentioned that there were **no written instructions** included with their medication,

> *"The last few times I've lifted from the chemist there's been **no paper inside** the box, I don't know whether it's because they only give you so many in a box or what and some just have the name written on it, it's not even typed out."*

A lot of participants admitted they **do not read** the written information provided with medication. One reason is the lack of understanding of the information provided,

> *"Nobody reads them [information leaflet in box] You can't make **head nor tail** of them."*

And feeling **frightened** by the negative information, including potential side effects,

> *"I think sometimes it's [written leaflets] a little bit too complicated...If you read it all you'd* ***run away****...There's more side effects than there is pluses with it too."*

It was mentioned that people may need the written information/instructions to be explained as they can be **complex**,

> *"Sometimes you might need some clarity on it. If you don't completely understand what it is because there's a lot of instructions written on it and there's loads and loads of writing on it."*

Community participants commented that the **timing** isn't always stated on labels placed on prescriptions for medication,

> *"There's* ***nothing*** *on my medication boxes to say when you take anything (P1) ... Same with me too, I just found out today the timing, it's not on my prescriptions either (P2)."*

And that instructions in medication boxes are not enough as they do not take **personal medical history** into account,

> *"Sometimes it says take it in the morning, take it in the evening but it doesn't always say but don't take it within an hour of taking this medication or that medication and that's something maybe your doctor or your pharmacist needs to do because the* ***manufacturer of the tablet doesn't know*** *what other tablets you're on."*

And the instructions are left for the participant to **interpret** in their own way can be dangerous for medication safety,

> *"That's in itself, "as and when required", that's so woolly and it leaves it* ***open for so much abuse.****"*.

Health and social care staff explained their views on the issues they see with non-direct instructions. One participant described a person interpreting the instructions incorrectly as they **weren't clear** and the medication being **less effective** as a result,

> *"It said two daily and they didn't actually understand, it was actually* ***long-acting medicine*** *that had to be taken together but this person said well, I'll take two daily, I take one in the morning and one at night which actually meant it was* ***less effective.****"*

Another described **frustration** with the instructions,

> *"I think it doesn't help when GPs put* ***'One Daily'*** *on the label, and if it is one daily, we have to put 'One Daily' on the label, we can't really change that. We can tell them to take it in the morning or the evening but it's more helpful if the GP puts the time of day on it as well."*

Medication names and packaging and lookalike / soundalike medications

Community participants also commented that look-alike / sound alike medicines are confusing and can lead to medication errors.

> *"They normally give me in those wee tiny plastic cups... I **can't tell by looking** at the tablets, they normally come in the packets therefore I ask them that they are separated from the other medications, and I know to take them at the proper time.s"*

HSC commented this applied to blister packs as well.

> *"It's confusing when it's coming from the blister pack as well because they all say **one small white** tablets but it could be four small white tablets so you don't know what tablet it is."*

Difficulties with lookalike / soundalike medicines were also raised in HSC focus groups:

> *"In my last job in learning disabilities we had a tenant that was on the same medication for a long time and the pharmacy had changed the colour of a tablet and he refused to take it because **it was different**, it was...the same medication but just a cheaper brand."*
>
> *"I've been in people's houses where one person had **three different versions of the same** tablet and was actually taking one of each because one of them was brown and pale brown and the other one was brown and orangey, and they didn't realise they were different because they looked different, so they were taking one of each."*

The **labels** on medication were also discussed as potentially confusing with understanding lookalike / soundalike medicines,

> *"I think definitely trying to inform people about their names. This obviously is complicated by the fact that the companies like to put the **trade name in big writing** at the top of the box and I always have to emphasise to them... it's that wee name underneath... We should have went to big pharma guys and sat in a room and decided how to make up names that no one can **pronounce**, how to just be twisted and awkward."*

4.3.3 Advice and guidance on medication

Community participants discussed their experiences of receiving **advice and guidance** from HSC about their medication.

Multiple participants had **positive** experiences of receiving advice and guidance from pharmacists about medication,

> *"I would **always check** with my pharmacist. When I was very, very bad with the sciatica and I said right, what can I take so he looked at my thing down in the pharmacy and he said yes, you can take this and rub it on topically because I couldn't take arnica to help."*
>
> *"I was in a group here [community organisation] and the pharmacist was out, and he was saying you know, you take that first thing in the morning before anything else, so now I leave it upstairs and as I wake up, I just take it then before I take any other medication."*

Community participants described some **negative** experiences of not receiving adequate advice/guidance about impacts and side effects of medication.

> *"I was on gabapentin for years and I don't think I was ever told any of the **backlash** of it from the GP, they just hand them to you very quickly and get you out the door."*

> *"I went to the GP for back problems, and I had an injection in my spine...and he told me to **stop** the tramadol and I was in bed for a week shaking and **withdrawing from it**...Obviously, I gradually could come off it, but he just told me to stop taking it."*

And not enough advice on how to take medication **correctly.**

> *"We're supposed to be able to trust them, we have to go home and research our tablets and find out...what side effects they're going to give us, they **should be filling us with all this information** before they even give you a box."*

As well as a poor information and instructions on how to take medication **safely.**

> *"For years I've been taking levothyroxine, **only recently found out** I should have been taking it half an hour before eating, and since in a week of taking it correctly I feel like a new person."*

This lack of information was also noted by HSC participants.

> *"People would be so used to getting a tablet, I've taken that tablet for so many years, but they might **not realise** they have to take it half an hour before food or at a certain time for it to be effective."*

A HSC participant also gave an example of a patient who was not given advice on how to take medication correctly.

> *"I had one service user who had thrush and she was give medication from the doctor, cream and a pessary and the wee lady was given **no information whatsoever** and nobody had talked her through what she was supposed to do with it and she tried to swallow the pessary, she actually broke it up and had swallowed the pessary instead of inserting it but that was due to being misinformed and she didn't obviously read the instructions.*

People in the community said they were not given enough guidance on **how long** they will be taking medication.

> *"But when they prescribe them, you need that knowledge. Or it is **long term and that's okay** but an agreement as to how to manage. I mean are you going to be on this medication 'til you're 90 or why do you need it and how long do you think you might need it for and where, you know..."*

Some noted that healthcare professionals can **assume** people in the community have the correct knowledge about their medication.

> *"My mum wasn't shown how to give injections. They almost **expect** you to be a medical professional yourself."*
>
> *"Medicine safety should start from who gives you the medicine. They can't expect us to be **medically trained** enough to know where, what?"*
>
> *"Having doctors actually explain...not how it [medication] will affect you but how it **can affect** you because I know I've been on medications before and I **wasn't even aware that that was a possibility** of a side effect and then when I went back to the doctor he was like – oh yeah, that's a very common side effect. And he said you should have read the leaflet."*

People in the community sometimes do not fully understand the roles of different HSC professionals, the help they can give and their responsibilities. Some community participants were **not aware** of the advice and guidance available in **pharmacy**.

> *I **never knew** you could consult your pharmacist about your medication, I thought you would have to go through your GP."*

Or as a HSC participant identified – how to **order a prescription.**

> *"And people…**don't know the whole system** where you have to order your prescription, the GP can arrange for that to be collected by the pharmacist. You go and you pick up your prescription or your pharmacy delivers it…I really took it **for granted that people knew** all that but people don't know that…letting them know that they have to ring up and order their medication so you have to really **educate people** about what you need to do when you're on medication, how you get the medication."*

And why prescriptions can't be given out **quickly.**

> *But what the patients don't realise is we can't just **wing out prescriptions,** we have a huge number of checks to do because we're processing literally thousands of prescriptions a week and we don't want to kill somebody **by accident**. And so, the reason we've got a 48-hour turnaround time isn't because we're lazy…but the patients wait until they completely run out of drugs and then want you to generate a prescription **instantly** and you can't do that because you've got to see all the patients waiting in the waiting room and there's a whole **communication** thing there that just isn't happening."*

And **who can write** prescriptions

> *"The amount of patients that would be like aww I'm feeling a bit sick or I'm feeling a bit down, you wouldn't just write me a script there and we're like **we can't just write you a script**, you need to go to your doctor…. I think a lot of service users maybe don't know that."*

A district nurse explained that they can **write prescriptions for some things** in the community, and this can be confusing for people.

> *"District nursing sisters are nurse prescribers and we do write prescriptions for quite a lot of things in the community, so they may have seen us writing scripts for dressings, catheters, there's quite a list on that form that district nurses can prescribe so, in that sense, patients might be a wee bit **mixed up** about who they can get a prescription from."*

And that there are other people in HSC that can give help with medications to those in need

> *"In some cases if there's no family and somebody is clearly not able to manage their medications I would ask the GP and ask the pharmacist to do a weekly dispense and do the blister pack and we are lucky enough in our area that we do have a good service for that but I do think they **don't understand** that it's something they may be able to **access."***

4.3.4 Personal experiences and research influencing their understanding and knowledge of medication

Participants gave examples of how their own experiences and research influenced them to stop taking medication or to not take it as prescribed. Some couldn't see the benefits of the medication; they were aware of the side effects and were concerned that they would outweigh the benefits.

> *"I thought I just don't like taking medication and I thought this is probably something, and when you read the bump that comes with it, it would **scare the life out of you,** and I thought there's too many side effects)."*

Some participants had **negative side effects** from taking medication previously, which **put them off** taking medication again,

> *"I had to stop taking it [previous medication] myself and come off it altogether. Through that, **I don't even take painkillers now**...but I won't take anything the doctor prescribes me if it's anything to do with altering my brain chemistry."*

And noted the side-effects can be **worse** than the symptoms.

> *"See that's the thing too, that they're so quick to prescribe tablets. They'd nearly give you anything and everything and some of the side-effects from the tablets are nearly worse than how you feel originally, or you feel **ten times worse.**"*
>
> *"I myself could see that he didn't need any of them, they weren't not doing any good and **making things worse** and then eventually they were taken all off him."*

Others noted how side effects of medication can result in needing to take more medication to **counteract** it,

> *"It's like I take Naproxen and then I have to take a stomach tablet **because of the acid** and all different bits so I'm putting another one in my body just because of that."*
>
> *"There's **three of mine that interact with each other** that I have to take all three but it's like if I take one of that then I'll get severe heartburn and stuff and then the other ones can cause low blood pressure if I take them together, so I have to time them (P1) ... That's where it gets complicated." (P2)*

Some were concerned about the **long-term impact** of taking medication.

> *"I just said to the receptionist, look, I'm not taking them anymore, I'm going to **need antibiotics in the future**, that's going to be obvious some time and I'm not going to be able to absorb them or get them to do the right job so that's why I stopped taking the tablets."*
>
> *"They're not going to do anything and I'm not putting tablets in my body that's not going to do anything and could **possibly affect something else**."*

> *"I think if she's [daughter] is sleeping around 11 pm that's enough for us but we have her on it now and I'm not going to put her on something she doesn't need to be on,* ***thinking of the livers*** *as well."*

Community and HSC participants noted people do not want to become **reliant** on medication.

> *"I, personally myself am supposed to take antidepressants and other medication for low moods but just can't allow myself because I don't want to be reliant on tablets and don't want to have to wake up every day and* ***be instructed by myself*** *to take a tablet."*

> *"And I think a lot of people are* ***fearful of becoming addicted*** *to drugs. Whether there's an addictive nature to the drug or not, that's their perception."*

A healthcare professional described how **perception of risk** can influence medication non-adherence,

> *"When you're talking to people about risks, for example, during that pill scare and you're talking about your risk of death on the pill is less than one in a million, you're actually more likely to get hit by lightening in some areas, they'll go –* ***that'll be me****. Because if they do something like taking a pill they have an adverse consequence, that annoys them more than the thought of you've got a 90% chance of getting pregnant in the next year if you don't take your pill."*

Some people feel the medication **isn't making a difference** and they don't take it. One person described how they never took their preventer inhalers for asthma.

> *"But I've learned as I've got older, and I take everything I'm prescribed for my asthma. I take everything. It seemed as if* ***I didn't really need it****. I just thought it was a bit of a faff, but I've learned over the years, and I definitely take it now."*

HSC participants discussed the challenges in educating people about the need for **preventative** medication.

> *"Some people really are quite concerned about the side-effects and that would put them off, particularly things like statins and even calcium tablets because they don't feel any different for taking them, they* ***don't think they're important.****"*
>
> *"A lot of people would think well my blood pressure is alright, I'll not bother taking that blood pressure tablet,* ***I feel fine.****"*
>
> *"So, people who have hypertension, people who have Type II Diabetes they do not feel unwell. But if you* ***don't treat*** *hypertension and you don't treat diabetes people end up in hospital with strokes and heart attacks and renal failure and heart failure but at the time you prescribe they are completely symptom free, so they feel I am taking this medicine every day and* ***I feel absolutely fine****, I don't want to be taking this because it negatively* ***impacts their self-perception*** *of being a well person and they are a well person, and suddenly having to take a tablet every day makes them feel like an oldie sickie person and a lot of patients just stop their medicines."*

And that it can be difficult for health and social care staff to **explain the risks** associated with not taking medication,

> *“Conveying concepts of risk to patients is fantastically difficult which is why we’ve got those nomogram charts and things to try and help us but patients **still worry** about something they’ve done to themselves like taking a tablet that might have an adverse effect even though not taking the tablet also has an adverse effect… Getting people to buy into and take preventative medication when they don’t feel ill at that moment in time which is reducing their risk of something in the **future** is astonishingly difficult.”*

A common theme emerged around people **using the internet** to research their medication and general health issues. Participants wanted to know general information about their medication when researching on the Internet,

> *“I may even have looked up on **Google** to see what the contraindications are and being convinced that it was not going to do me any harm.”*

People continue to do this due to previous experiences of **finding answers** on the Internet,

> *"I keep looking up all the tablets **on the Internet** now to see what the side effects are, if you can take them with other things and stuff because I remember my mother in law, she started taking wild dizzy spells and falling all over the place and I looked up all her medications and **two of them said do not** under any circumstances take these two tablets together, it causes dizziness and you might fall."*

Health and social care staff explained the **danger** of using the internet in leading people going against healthcare professional advice,

> *“I had someone recently who stopped taking it because he went to research what he was given and he says there was two cardiac drugs prescribed by a consultant and one by a GP but in his reading of it he was saying well, they do the same thing, why would I be taking both of them. And rather than come back and ask a professional for advice **he stopped taking them** and was disposing of them.”*

And this negatively impacting their health,

> *“I have a lady who had two mini strokes before, very strict vegan, thought she could control or prevent further strokes by managing her diet…and of course she took the third really severe stroke that has completely affected her mobility and every aspect of her life but my first home visit with her she completely broke down in tears with **massive regrets** for not taking her medication…she’s really, really strict and even still to this day she still is, but she’s got massive regrets about not taking her preventative medication.”*

Health and social care staff explained that people use the Internet to access information **before allowing** the tablet to start to work,

> *“Sometimes you get very intellectual professional people and for whatever reason they either only hear what little bit you’re giving to them, and they **miss the bigger part**, and they go away, they go to Dr Google, they’ll get the side-effect side of things, and they haven’t really fully given it a chance for adaptation to take place where the side-effects level out.”*

4.3.5 Other people in the community influencing people's knowledge and understanding of medication safety

Friends and family

Many participants described the influence of friends and family in their decisions about medicines. One participant explained how he decided not to take a medication due to **listening to other people**'s perceptions about the medication.

> *"I just...I just hear a lot of people, I was* ***listening to other people*** *saying oh I can't take them, they're no good, they're damaging."*

Many participants noted their **friends and family's experiences** of side effects also putting them off taking medication,

> *"One reason I don't take them is because of the side-effects because my granny had osteoporosis and then my mum, and three of the medications I'm on can cause that. But I need tablets for pain if you get my meaning, but I don't want to take them and* ***risk me getting something else***." (
>
> *"I'm nervous to take them because my husband who does have depression has been on them previously and* ***I noticed the change in his behaviours.****"*

As well as **not administering** medication to family members due to their own feelings of not liking medication,

> *"I was thinking these are useless, they're no good to me. But come towards the end of the school year and the summer definitely, whenever he has levelled out completely on him, I am seeing a world of difference and they are helping. They just did take the time and I wasn't giving them the proper chance because I* ***don't like medication myself****, so I didn't really want to give it to my child."*

Health and social care participants were also aware of the dangers of families influencing medication safety.

> *"And negative information from untrained people, so relatives who give them* ***bad news stories*** *about drugs and they just decide I'm going to stop that without ringing up and chatting it through with anybody to know why actually it's quite important you do continue that medication."*

Media

Many participants came across information on **social media** about medication, and using it to make their own conclusions about their health,

> *"Social media seems to rule a lot with medication that you're taking...people look up social media to find out what the effects are and different things. I know it's written down...but...going through every tablet you take to read all the conditions for it. I think people are using social media to even* ***self-diagnose.****"*

Many were also aware that social media is **not always a trusted source**,

> *"How dangerous this is, it's all the **misinformation** that we're getting on YouTube or whatever it is on the channels that we're getting and yet, there's nobody here to say look, this is not right, they're scaremongering or whatever. We don't have access to information here to combat these things."*

Participants described experiences of seeing their medication being **mentioned positively** in the media,

> *I don't know why I take this Simvastatin; it's frequently mentioned in the press as being **highly recommended** sort of thing."*

Health and social care staff noted that information in the media can put people off taking medication and warned of this negative impact on medication safety,

> *"We had a load of people stop their pill when there was a media scare about the pill even though it really was irrelevant because they had a safe medical history but because it was **bad publicity, they stopped** their pill, and some got pregnant as a result. Similarly with statins, every time The Daily Mail publishes **a negative news article** about Statins, we get a stack of people who it's actively dangerous for them to stop a statin, they're maybe sitting there with a couple of stents in their heart which will reocclude without their statin and they stop their statin."*
>
> *"They've maybe heard something in the media about a drug and they think no, I'm **not going to bother** with that anymore. Or maybe there's a particular side effect that they just are concerned about, and they don't want to take it. They've got a notion into their head, and they don't want to take it but if they don't tell you, it's very hard then to know what's going on at home."*

Summary: Health Literacy

Community participants shared their experiences of accessing, receiving, and understanding instructions, advice, and guidance with their medication. HSC participants also shared their experiences of supporting people with their medication. Many people experience low health literacy which was presented in different ways, for example:

- Not being aware of the importance of taking medication safely, including the harm that could result from stopping, mixing, or sharing medications.
- Being unsure of their medication's name and purpose.
- Being unsure about the process to get a prescription.
- Not understanding the benefit of preventative medication.
- Not understanding why a certain medication has been prescribed and concerns that medication is prescribed to benefit health and social care and/or 'Big Pharma'.
- Not being aware of the advice, guidance and support that pharmacists and other healthcare professionals can provide with medication.

Community participants health literacy was influenced by many different sources including friends' and family members' experiences, their own research, social media, and stories in the media.

Healthcare professionals can sometimes assume people have higher levels of health literacy and have the correct knowledge and understanding about their medication. Community participants felt that it should not solely be their responsibility to remember or know what medication they take and voiced that they need:

- More support from health and social care professionals
- More information and guidance about medications
- Clearer instructions on medication about dosage and timings. This is particularly important when it comes to look-alike and sound-alike medicines.

4.4 Theme 3: Reporting issues and concerns about medication

This section is about people's experiences of reporting issues and concerns about medication. Making decisions about medication is covered in the next section (4.5).

4.4.1: Positive experiences to reporting

Many of the community participants had positive experiences of reporting issues and concerns about medication to healthcare professionals. In most cases the person had spoken to their **pharmacist,** and they were able to give them advice.

> *"One time I was taking tablets and they made me sick all the time, so I stopped taking them. And then I told the chemist they were making me sick, the **chemist said to stop taking them** because they were really making me violently sick."*
>
> *"I was buying some of them to help me with my pain and I thought oh, these are great and then somebody said you shouldn't be taking them with them tablets but sure I didn't know… It was the wee pharmacist in the shop said to me, are you taking them with your medication? I said yes. He said **no, you can't."***
>
> *"I go to the same chemist all the time and one day I had a cough and the girl was going to give me something and the chemist came down and said no, you're on such and such tablet, he said because you have paracetamol and you don't want to mix with that, so I said to myself after that just keep going to the same chemist because **they know you and keep an eye on you.**"*

One participant noted a pharmacist was a '**lifesaver'** as they noticed they had purchased a lot of over-the-counter medication

> *"I was buying Ibuprofen over the counter, and I was going to different chemists all the time because they would only sell me so much, I think it's a box they'd serve you, but I ended up going to different chemists and one of the chemists copped on… **she's a lifesaver, she tried to help me**… I was taken into hospital there a couple of years ago and I was very sick. She was, she **stood by me**. I mean that year she said to my sister – your brother is going to be found dead, and I was taken to hospital a month later."*

Other participants described going to the **GP** when they had concerns about medication and changes being made.

> *"I forgot to take my medication…, but I did contact them [GP] and say look, I have been completely doolally for three days and I asked is this possibly what has happened here, and they were able to confirm that that was the case which then made me really **question** the dosage I was on, I've been able to wean myself back."*

HSC participants spoke of experiences when they **gave support** to people after they reported they hadn't been taking their medication.

> *"I had one lady who stopped taking the blood pressure tablet because she decided **it didn't agree with her** but **didn't want me to let on** to anybody. And I had to be very firm with her and say look, I know I've only just met you and we're building relationships here but I can't*

> *because if anything was to happen to you tonight I couldn't live with that and you couldn't live with that and your family, so she agreed that I could ring her daughter while I was there and the daughter then took it forward with the GP and pharmacy."*
>
> *"Women are very honest, they'll say look, you're going to have to put a coil in for me or give me an implant because I literally cannot remember to take that pill, my lifestyle is too chaotic or whatever, I'm going to end up pregnant because that pill, I'm only remembering it about four times a week. So, when it's something like that they generally are **extremely honest.**"*

4.4.2: Negative reporting experiences

Community participants described negative experiences when they reported issues with their medication. Some had experiences of health care professionals **not listening** to their concerns.

> *"She went and told the doctor [she didn't take her medication] and the doctor said, I prescribed it to you, you take it. And **didn't listen to her.**"*
>
> *"That one I was allergic to, I told them I wasn't taking that anymore, I said my blood pressure since taking it has gone through the roof so it's not doing what it's meant to do and I can't work, I can't even hold a cup of tea, can't do anything, can't dress myself, can't even walk, had to crawl on my hands and knees to the toilet and everything. I says, I can't live like this, and **he says well, you have to**."*

Some participants felt that they were **criticised or judged** by HSC professionals when they reported medication errors.

> *"Yeah, when I've missed a few and they're like well you **can't be in that much pain.**"*

Another described a mistake a GP made with a prescription for their child which they reported. This resulted in the GP blaming them for giving the child the medication incorrectly.

> *"Or you get a GP that prescribes you the wrong medication and it's three times the dose and after three days I wondered why my child wasn't on the planet and realised the doctor prescribed wrong… **I was called a stupid mother** that I was giving her the wrong medication and it wasn't me, after three days I said there's something not right with this…**I left the practice**, I couldn't cope with them anymore."*

Participants who had experiences of **poor mental health** felt **criticised and judged** when they took their medication incorrectly. One participant described their experience when they took an overdose.

> *"When I went to hospital with the overdose the doctors there were really criticising me, they were like "well, that was a silly thing to do, **you should be more sensible** with medication", I even had a nurse say I shouldn't be in charge of my own medication which, at the time felt very degrading. Obviously, I fully agree I shouldn't have been in charge of it myself but at the time when I was in that place it was very **degrading.**"*

Another who stopped taking their medication didn't feel the conversation with the doctor was **supportive.**

> *"It [prescribed medication] brought on psychosis, I was having hallucinations, I was being abusive to my family and friends, I was just walking on air really and I was completely a different person, I didn't know what was going on around me for a long time which then obviously caused more problems than it's helped. And when I was eventually forced to go back to the doctor, I was out of it, didn't have awareness that there was an issue, my parents actually just forced me to go back to the doctor and the doctor said, well, **why did you come off the medication**, why did you stop your medication."*

4.4.3: Barriers to reporting

Negative feelings associated with reporting

Community participants spoke of the reasons why they wouldn't report medication issues or concerns. Participants felt that by reporting concerns they were **bothering** their GP.

> *"I'm feeling that I'm a **nuisance** and I'm not somebody that is constantly ringing up or perhaps I should. I'm trying to be understanding to their predicament."*

There was recognition that people frequently don't take their medication as prescribed, and it would be **too much** to phone the GP every time.

> *"If you reported it to the doctor every time you didn't take your medication sometimes properly, I'd say I'd be seeing him **once every month.**"*

Others felt they would be too **embarrassed** to admit to a health care professional that they didn't take their medication properly.

> *"You wouldn't want to go and admit that you **aren't even capable** of taking two tablets…Sure as that man said earlier, you **won't make an ass of yourself** walking in and telling them you done something like that…You'd **rather suffer.**"*

HSC were also aware of the **embarrassment** people can feel,

> *"So sometimes I think you will get people that will tell you and then there's people that maybe are **ashamed** and won't tell you."*

Not seeing the need/wanting to report

Some people only felt there was a need to report medication errors if they had immediate **adverse effects**.

> *"I think the only time you would do that is if what you did **made you sick.**"*

Some HSC participants commented that people **do not realise** the error might be creating long-term damage and do not feel the need to report.

> *"I don't think they realise and then whenever they tell you, you go you do realise you shouldn't be doing that or you're really overdosing, you're putting your liver under quite the strain…So, whenever they realise, they sort of go – **oh, I didn't know that.**"*

Some participants described how they been prescribed medication by their GP, but don't take it as they want to **please the GP** and don't tell them.

> *"I stopped taking my medication too. Just took myself off it.* ***Thank God the doctor didn't know****… I do lift it like, but I don't take it… I just throw it in the bin… A drug bin down here."*

Wanting to please the GP was also raised in the HSC focus groups.

> *"I will bring that up about medication and usually it builds up enough to report oh god, the* ***doctor will probably be cross*** *that I'm really not taking that."*
>
> *"They probably feel it's wrong, the doctor prescribed this. Some patients are very* ***reluctant*** *even to mention to their doctor they're not taking a tablet and will continue to order it and still not take it."*

Lack of time to report.

Another barrier highlighted by community participants was the difficulty in getting an **appointment** with GPs to report medication errors.

> *"Sure, you* ***couldn't see a doctor to tell him*** *anyway. So how do you see a doctor, you tell me, how do you get in touch with a doctor?"*

And when they do get an appointment, there is **limited time** to talk about not taking their medication "

> *"Well, that's it, even to talk to them about important things, things that are really important is* ***a fight*** *so to talk to them about forgetting something or you know, something that wouldn't be that important to you."*

Fear of consequences

In the community focus groups, participants discussed how they were afraid to report medication errors due to a fear of **what would happen** to them and their families.

> *"Maybe we would be too worried to admit that you screwed up, you might think something is going to happen to you…so you just* ***keep it secret.****"*

Those participants with children had a fear it would be **reported to social services.**

> *"At the time my boy was 12 you were afraid to say anything because it would always be the fear of Social Services will now get involved and I already have enough stress factors going on in my life never mind thinking is my child* ***going to be taken from me*** *because I'm having issues with pain medication that you put me on in the first place."*
>
> *"Even Social Services need to be seen as more of a support network too because it's very much* ***women are afraid*** *to go – I'm struggling because of fear of the kids being taken and really, that shouldn't be the way."*

Or that they **won't get any more help** if errors are admitted

> *"Whenever I took myself off my medication my doctor just went* ***– I can't help you anymore then****. You can't see a psychiatrist unless you're on the medication we put you on."*
>
> *"If you miss them [medication] then you worry about being* ***judged*** *by the doctor because they're not going to help you if you don't take them."*

HSC staff commented that when people are older or need a lot of support, they are reluctant to report errors as they **don't want to admit** they are struggling

> *"Some people don't want to say either that they're starting to struggle to manage. You know, if it was someone that was always competent in managing that before it can be very **difficult for them to say** well actually, I'm finding it harder to remember what I took or I'm finding it harder to orientate myself to the days of the week and maybe that's the first time they've really acknowledged that there's a difficulty because sometimes people will try and cover it up to create the **illusion they're coping.**"*

There is also the fear that their **independence** will be taken away.

> *"They're afraid to tell you if there has been any errors or anything because they really don't want to lose that wee bit of independence, that wee bit of control that they still have because a lot of people whenever they have care teams and stuff coming in, they do feel that their independence has been taken away and they've lost that wee bit of liberty…and if they do make a mistake they're afraid if they tell us that whenever we report it back that that wee bit of **independence is going to be taken away** from them."*

Disposal of unused medication

Many community participants did not know where to safely dispose of medication that hadn't been used. People didn't want to bring it to the pharmacy and admit they hadn't been taking it. Most didn't know about the RAPID drug bin initiative,

> *"Probably if everybody here looks in the cupboard, they've got it. **What is the official line**? One has enough sense not to put it in your bin. What are you supposed to do with it?"*

4.4.4: Enablers to reporting.

Community participants didn't speak a lot about enablers to reporting. One participant described how if a health care professional is **approachable**, they feel more comfortable to engage with them.

> *"He was like – I completely understand because I said to him, I don't want Social Services thinking that I can't manage with my kids and he said they're not going to think that, and I felt like **I could open up** to him because of the way he approached me."*

HSC participants felt that many people wouldn't report concerns **without a prompt** from them.

> *"They [patients] would be very reluctant to say that to you. It would be usually us mentioning it to them, you always have to **start the conversation with them.**"*

HSC participants emphasised the need to build **good relationships and trust** with people.

> *"I love getting to know all my patients and I know the majority of them and will ask them how they are and things but you find with some of them when you don't kind of have the relationship you **can't get an insight** into what's going on and for me, that's a massive thing."*
>
> *"So, it's me as well learning not to do the whole kind of I'm the healthcare professional and I know all about it, **it's kind of trying to shift the power to them to let them feel they can trust and be honest with you** because at the end of the day that's the only way you're really*

> *going to get to the bottom of the issues and concerns that each one has, either individually or as a wee family unit, whether it's a husband and wife supporting each other or a daughter or carer's stress."*

And the importance of being **open and non-judgemental.**

> *"If you're non-judgemental and they get a* ***chance to get to talk to you****, which is the other thing because we're so busy, providing you're not all preachy to them patients will normally tell you forget that, I can't remember to take that or that makes me feel crap, can you give me something different."*

And they need to recognise the **individual's circumstances.**

> *"I've seen nurses and other healthcare professionals that can be quite strict and they're doing it out of the good of their heart but that's not working for that service user, you have to be more like* ***on their page****…. so sometimes I think they have to change your approach to each person, it can be different."*

HSC participants also noted the benefit of using positive **language and humour**

> *"It's also language, it's not saying well, have you missed your medicine, which is very accusatory because they'll say oh no, no I haven't…so it's almost like* ***normalising it****. Well, how many times in the last week did you miss your medicine because that means it's quite normal to miss your medicines, it's not a problem. Just let me know. So, suddenly it's* ***not as threatening.****"*
>
> *"Trying to do it with a bit of* ***humour*** *as well so it doesn't feel like I was telling her off or undermining her or disempowering her, it was just lord almighty, what are you telling me that for, I can't sit on that. Trying to do it in a* ***gentle way*** *but also getting it done."*

Summary: Reporting issues and concerns about medication

People had positive experiences of reporting medication issues including healthcare professionals listening to concerns and changing their medication. Negative experiences included healthcare professionals not listening or patients feeling criticised or judged when they reported an issue.

- Enablers to reporting included:
    - Healthcare professionals being approachable, personable, open, and non-judgemental and recognising everyone’s personal circumstances.
    - Good relationships and trust between healthcare staff and patients.
    - Healthcare professionals starting the conversation with the patient about medication issues.

- Barriers to reporting errors and concerns included:
    - Not realising they are taking their medication incorrectly and not seeing a need to report.
    - Not knowing the importance of reporting errors.
    - A fear of repercussions e.g., social services involvement.
    - Not knowing how to report, who to report to, or what happens when they do report.
    - Not having the confidence to start a conversation with a healthcare professional.
    - Feeling embarrassed to admit to health and social care staff that an error was made.
    - Wanting to please healthcare professionals.
    - Not wanting to bother the GP.
    - Getting a GP appointment to discuss concerns.
    - Being unaware of how to dispose of unused medications, e.g., in a pharmacy, to have an avenue to discuss why medication was not being taken.

4.5 Theme 4: People being involved in decisions about medication

This section is about people being involved in making decisions about their medication, including medicines reviews. Community participants may not have been involved in the full implementation of a Shared Decision Making process. This is a process which simultaneously combines the expert medical knowledge of the clinician with the expertise of the patient, who understands what matters to them and the relevance of their own values and priorities.

4.5.1: Positive experiences of being involved in decision making

Several participants were able to describe positive experiences of being involved in making decisions about their medication.

Changes in medication

Participants described speaking to their doctor about medication and their **doctor working with them** to get it changed.

> *"My doctor is really genuine, like I started on 50mg of Sertraline and I was like, this is not working, I'll just not take it so he* ***gradually put it up and he rang me two weeks*** *later asking how I was feeling and things like that, like I've not asked for him to ring me, do you want me to put it up anymore, like put me up to the maximum dose and then he was like what do you feel if I gradually start bringing it down and see how you do feel…I feel comfortable opening up to him like."*
>
> *"I've actually the best GP…Because if you want to discuss something and you ring up in the morning, they'd get somebody to* ***phone you back within two hours****, say I didn't want the medication or something I could just go on and say to the doctor it's not helping me, and* ***they'd take you off it****."*
>
> *"I took a statin, and I went into the doctor, and I said they're not agreeing with me. [The Doctor said] Aye, we'll just take you off them then."*

Community participants described the role **pharmacists** have in helping to decide to change medication.

> *"I went to the chemist, and I said to him look, I've been prescribed this but* ***I've a feeling that it's not right****, so he* ***checked it up*** *and he said yeah, you definitely shouldn't be on that however, you do need whatever it was prescribed for. So, he* ***contacted the surgery*** *and then they got back to me then and sent the right medication that was needed."*

Other **HSC staff** have also helped people make decisions about their medication.

> *"It was my occupational therapist, they were the one that forced me to get the tablet review, they got me registered to come in here [support group] like she* ***had taken the time to actually read your notes*** *and know what was coming in before you came in the door and sat down and had a plan in place rather than you just looking at her and her saying you need to come back for another appointment after I've read your notes."*

Involved in making decisions.

Many of the participants were able to provide experiences in being involved in making decisions about medication.

> *"When I was up at the hospital, they gave me my say on blood thinning tablets, they said you had to be over 65 to take these and then there's a point system kind of gradually goes on from that, kind of how you take them…because I was 64 they* ***left it up to me*** *whether I take them and that was a consultant in the hospital that left it up to me, not the doctor, a consultant who was checking because I had a wee bit of fibrillation in the heart…* ***I was surprised*** *at them leaving it up to me and then the fear factor comes in and you say to yourself, I'd rather take these."*
>
> *"I was in the hospital after Covid and the girl said to me your heart is out of beat, we've got to give you tablets or you're going to take a stroke and she* ***explained it all to me*** *what it was for."*

A participant described how they were prescribed a tablet for Lupus that affected their eyesight. They had a conversation with the doctor to decide whether they should **continue to take them**

> *"They were flashing all these lights at me and darkening the room down and flashing lights, it was the craziest thing I've ever had done to me. It was horrendous. I said,* ***what's all that about?*** *Because you're on hydroxychloroquine it can affect your eyesight and I went, well I'll tell you what…because they said if the lupus, you can end up crippled and stuff, but anyway, I said I think I'd rather have my eyesight."*

Parents also spoke of experiences discussing their child's medication,

> *"We got her [participants child] ADHD diagnosis at the end of April, she had done the screening in January but by the time we got a review appointment and the consultant at the hospital gave us the option as parents – do you want to go away and read the information and find out about this? And sort of talked us through the side-effects and whatever or are you happy enough. So,* ***I feel we were given a chat.****"*

And recognition that there have been **improvements** particularly with MDTs.

> *"Now it's getting a bit better with the whole MDT but that medical model…so whenever you go in for an appointment about something they don't ask about other things that could be impacting on that something. Like your mental health. Well,* ***what is going on for you*** *that your mental health is like… You'll get the odd GP who is quite good, but they'll just say right, let's try another medication or that medication mustn't be working for you, let's try another medication. It's that medical model of things."*

A HSC participant described how they have **helped patients make decisions** about their medication.

> *"This gentleman, I said what am I going to do to help you, what's the problem, ah well there was alcohol issues there as well, he was on his own so there were a few issues going on. I said,* ***what would help you?*** *And he said, well I'd like to take them all in the morning, I don't like*

> *bedtime. So now I'm working with the GP and the community pharmacist to switch it to a once-a-day medicine and that's what he asked for and then I'll follow him up to see if that helps. I've just written up one where it did help, this gentleman was forgetting to take his metformin at teatime, he had low mood, he really didn't take it, he always forgot it, his diabetes was very poorly controlled, we flip that back to the morning with the GP practice pharmacist and the community pharmacist and* ***he's managing fine now*** *because he can remember morning."*

4.5.2: Negative experiences regarding decision making

Opinions not listened to

Many participants described experiences where their **opinions were not listened** to regarding their medication.

> *"They wouldn't review any of the tablets...and then any time I'd try to talk to them* ***it was going over their head.****"*
>
> *"[participant said to the doctor] '****you don't understand****, I'm in massive pain and all you're giving me is paracetamol and tramadol' and then I got the right medication eventually."*
>
> *"I had to wait a year which is quite good for waiting on the NHS and he [doctor] said to me, 'I think your medication is working and you don't need it'. I said, '****you're not in my day-to-day life'****."*
>
> *"I want to come off my antidepressants because I know I've been on them for a long time. I've once again mentioned to a couple of health practitioners that I want to do this, and I know I will need support, that I shouldn't just stop but* ***nobody is addressing it*** *and I don't think they're making any difference."*

People feel they have been prescribed a medication which **will not address their issue.**

> *"I don't have depression, I contacted the doctor about my anxiety and was already on anxiety meds and he's given me antidepressants and I said,* ***I really don't want antidepressants.****"*
>
> *"I was handed antidepressants when I had menopause symptoms. And I know there are studies that have shown that maybe antidepressants do help with it, but* ***mine wasn't mood****, mine was sugar cravings, joint pains, hot flushes, it wasn't depression it was menopause. Give me the gel please!"*

People have felt the medication isn't making a difference and they're **told they have to take it.**

> *"I went to them and said to them look, there's been times where it's been a month and I said I don't really notice any difference. The only time I will notice is if I'm trying to diet and it's not coming off cause maybe I'll know it's that level, but I've went to them and said look, you've seen my levels, I'll go and get them done now and there'll be nothing, but they'll say no,* ***you have to take that****, that's part of your underactive thyroid. It's a lifelong condition and they say basically that you have to..."*

> *“You look up to see what it is, and they said not to be taking it more than four weeks and I’m taking it two years now. When you get tablets like that and then you ask the doctor about that, he says “don’t you be looking up anything on the internet!* ***What I gave you, you take.”***

Changes to lifestyle have also not been discussed.

> *"I’d rather bring my cholesterol down but that wasn’t even discussed, it wasn’t even suggested* ***would you try*** *to introduce a really low-fat diet and come back to us, and have it rechecked and see if that would maintain the correct levels."*

This has led to people getting the prescription and **not taking them.**

> *“Sometimes the doctor doesn’t listen to you when you don’t want a tablet and they say oh, well you might need it and they just give it where if you want to give it, I’ll take it and* ***get rid of it myself****."*
>
> *“I didn’t want to take statins because of the pain I’m already receiving, and I do know that they may induce further muscle pain, so I said I didn’t what to be prescribed statins, picked up my repeat prescriptions and in there was statins. But I didn’t realise at that time until I’d got home. So, I took them back to the pharmacist and they were actually just then* ***wasted medication.****“*

Decisions made without discussion

Community participants described experiences where HSC made decisions about their medication **without discussing it with them.**

> *“I’ve been on a bone density table from I was in my 40s…I was on one wee tiny tablet on the Wednesday, and they said it was going to be for the rest of my life. Well now I am starting to get twisted fingers and stuff… When I rang up for a repeat prescription I went to the chemist then I looked at it and I went back and said you forgot to give me it and he said no, that they had stopped it, the doctor didn't give the prescription and then I phoned…and I explained to her and she said no, when you get to 70* ***you don’t get it anymore****. I said why, that’s age discrimination, plus I need it and I think it’s been working great. I’ve pains in my feet, I’ve frigging pains everywhere now.”*
>
> *“I took a heart attack in June past and was took to hospital and they started to do blood tests and… the nurse said to me, ‘when did you stop taking the [name removed] tablet?’ and I said, ‘I hadn’t a clue when I stopped it, I just get my tablets from the chemist every week’. I said, ‘I stopped no tablet’, she said ‘yes, you did, it’s not on your list anymore’. It was a cholesterol tablet, and I says* ***I didn’t stop it, the doctor stopped it*** *at some stage, and she said, ‘they shouldn’t have took me off that tablet’ and I wasn’t informed, I wasn’t told [I was no longer getting the tablet].”*

And also, as a parent about their child’s medication

> *“So, when my daughter was diagnosed with ADHD within ten minutes of being in the room, they said she’s got ADHD and I just seen him writing and I was handed this script, she was six years of age. I was gobsmacked and like what have they handed me so I went and researched*

> *it and said they've given me this medication, **they haven't told me any interventions** that I can do anything like that, I was like no, I'm not going to do that."*

Exit plans for coming of medication have not been explained.

> *"I did have depression at one time many years ago and after maybe I think it was seven or eight years I said when do you come off these and he kind of went well, **after you've been feeling okay for a good two or three months, well that was maybe three years ago.** No one told me that that's when the exit plan, there was no plan to come off, you know, you just were prescribed them over and over again... Oh I had, they gave me the exit plan once I had stopped them myself like a fool."*

And **side effects** have not been explained.

> *"I was on gabapentin for years and I don't think I was ever told any of the backlash of it from the GP, they just hand them to you very quickly and **get you out the door**."*
>
> *"They're not providing the quality of duty of care to the patient if they **aren't looking at the whole picture** of what else you're on because you could be damaging your liver with all this medication as well."*

Some noted no consideration was taken of how medicines make participants **feel.**

> *"If I take my tablets in the morning **I don't function** until at least one o'clock in the day. I have sleep apnoea too, so they throw tablets at me. I said **I don't want more tablets.**"*

HSC participants were aware that **more work needs to be done** on shared decision making.

> *"We've a huge amount of work to do around this concept [shared decision-making], it's grossly lacking across the systems where the specialists start something and they just **move through the system**...you have your heart attack, you're given five drugs, discharged. And that's standard, and I'm sure if you then received me in through the door and I wasn't on my five you'd be ringing up going – why aren't they on their five? So, I think an NHS full stop, shared decision making is weak. We would have pockets of excellence but it's not wholesale by any means."*

4.5.3: Availability of medication reviews

Certain medical conditions

Community participants with **certain medical conditions** such as asthma or diabetes could give their experiences of regular medicine reviews.

> *"I have asthma, I have an asthma review **every year without fail** and that's only for an inhaler so they should be giving you a review of all pretty strong medication."*
>
> *"I've got diabetes and I'm reviewed every 12 weeks. I get **letters from my practice** to say you need to come in for your bloods and then make an appointment with your diabetic nurse, and they're very good...she'll look at, well I don't think that's working so we'll try this tablet. So, I feel that I am getting my medication reviewed".*

However, **some with diabetes** said that didn't happen.

> *"But then my husband has diabetes, and* ***he went for two years without*** *a review."*
>
> *"I am diabetic, and I* ***have never had a review****, I keep taking the tablets they prescribed me…Nurses or nobody seen me, end of story for three years there roughly."*

Lack of reviews

Many participants stated that they have **never had a general medication review**, or it had been a long time since the last review.

> *"We* ***don't get reviews anymore****…but do you see for us taking the tablets and being on them for a length of time how do we know,* ***how can we, ourselves, users say oh, I've had enough?*** *How is it sensible to know right, okay you can slow down on it, you can cut it down for our health without damaging your health by cutting down. There's no guidelines... You're continuing on, you're just hoping for the best."*
>
> *"I was on the highest max dose of this antidepressant that has so many side effects and nobody ever told you and they just left you, see you later, you just picked up your script every month because you thought obviously, they must be looking at this,* ***they must think I still need it.****"*
>
> *"I've been on antibiotics, I have a chronic infection, kidney infection and blood in the urine all the time. Now, it's been going on for a couple of years now and they started me off and I was getting courses of antibiotics, four and five times and then I'd have a spell and then another flare up and that and then they put me on this low dose for supposed to be three months but it was four months there just recently and I rang them, couldn't get talking to a doctor, no doctors available,* ***nobody there that could say yes, take them or no****, you don't need them."*

For some it was only when going into hospital or getting tests done that it was realised there was an issue with the medication

> *"I've just had blood tests for cholesterol and thyroid, and I haven't had them done for* ***over three years*** *and it was only because I had to have this medication review for another appointment. That was on Tuesday, I had a message this morning to ring the surgery, they've discovered,* ***now I realise*** *why I'm up two or three times a night with cramps in my feet and today driving up my hands were locked like this on the steering wheel and I'm shaking them to try to get the cramp out. Very low sodium level."*
>
> *"I was on tramadol for years and then I fell, and the hospital immediately took me off them, and I don't know how many people I've heard recently have been taken off tramadol,* ***is the doctor not supposed to check*** *if you're on long term medication like that."*

Patient demand

Almost all the community participants were **open** to having medication reviews and felt they would be very beneficial.

> *"I think it should be* ***part and parcel*** *that if you're put on something that's meant to be long-term by your GP it should be reviewed monthly and then maybe three monthly and then yearly."*

> *"Well, **it would be nice** to get a review on your tablets every so often, every couple of years even."*
>
> *"I do think if there's going to be any way to **improve** there needs to be more reviews within the GPs."*

HSC participants also felt there is a demand for reviews,

> *"The majority of the people I work with **if they were offered a review they wouldn't miss it,** I don't think, unless we were really stuck for transport, transport is a big concern. But if they were given that opportunity, they'd most certainly take it if they were able to access it."*
>
> *"Some patients are **very happy to take a phone call**, if they don't take the phone call, we send them a text message saying we're trying to get in touch for a chat. Usually, they'll phone us back… Most people want to review, they're glad to get **a chance to talk through** their drugs."*

And also emphasised the importance of medication reviews.

> *"They'll take them for maybe a few weeks and then they'll just drift away from them, and they won't tell you until you do their next diabetic review, and you look at their prescriptions and **you realise oh my god, they haven't ordered anything for three months.**"*
>
> *"There's so many things go on which is why you need the six-monthly medication review otherwise you would **never know what was going on with them?**"*

4.5.4: Alternatives to medication

Many of the community participants expressed a desire to reduce or stop taking medication and would like to explore alternatives. There was a perception that prescriptions are given out when they're **not always the best remedy.**

While some people do want to get a prescription for medication,

> *"I think there's a breed of people that **aren't happy** unless they're on tablets, and there's another breed of people that don't want to be on tablets."*

Many felt that they were given out **too readily** without looking at alternatives.

> *"If someone is coming into them as someone that needs help, like you're told to go to your health professional if you're feeling these thoughts but if they're not directing you to the right place or they're **just shoving medication at you it's not going to work."***
>
> *"The other thing too is that often times you could be diagnosed with something and that something might not be terribly bad, you might be able to live with that and don't need medication but sometimes I think it nearly goes **hand in hand** with the GPs that if there's a diagnosis, we must provide something."*
>
> *"Some of them [GPs] are old school and they just be thinking oh, he's sad, keep him on an antidepressant. No, send him to a counsellor, **do something that's outside of the box of tablets.** Or you go in – oh, I've got a pain. They give her a script. No."*

A HSC participant acknowledged that sometimes a prescription **isn't appropriate.**

> *"Sometimes the patient is 100% right though…So, sometimes we're using drugs to treat things inappropriately but it's not because we're stupid or bad, it's because we **cannot get people access to clinical psychology** and a higher income and better housing and all the stuff that would actually make them feel better so they are appropriately stopping the medicines because they worked it out for themselves."*

People explained why they **wanted alternatives** to their current medication.

> *"I went for a long time without any prescribed pain relief, but it just got to the stage where it made the difference between me just not being able to go out or go out. So, it was a vicious circle, if I didn't go out, I was missing that social contact and it was bad for my mental health, but this is what's getting me depressed really, the fact that I'm on this medication and I don't know for how long I'm going to be on it. I just **would like to have a word** with somebody about other alternatives to it."*
>
> *"When I went to the GP it was more, I was looking for a holistic which I think would be good if they would use that more rather than just reach for a prescription pad and say that's all the help you need because that's not what you're looking for because sometimes a massage or a talk to somebody does just as good as a tablet."*

Being referred to **other support** within HSC is welcomed.

> *"I had a positive experience in that I was referred to the mental health practitioner within the surgery and she rang, she was lovely, and it was her that **told me about here [community support group].** So that was very positive."*
>
> *"I was very low you could have phoned up and they'd say look, we'll get somebody, it might not be the mental health practitioner, but **we'll get somebody to give you a ring**, a wee nurse or something which they did."*

And interventions **alongside** medication

> *"Do they really need to be on that medication, like what's the benefit of that. Or mental health stuff I've a real thing about overprescribing mental health medication because I **think there has to be intervention** alongside."*
>
> *"It's the same with ADHD medication, that medication is fine but if there is no intervention alongside that that's not going to work, **they work better together.**"*

One participant spoke of a positive experience of a GP **understanding** that they didn't need medication.

> ***"**I was going through, a very, very difficult time and I was very, very stressed and I went to my doctor, and I said is there any possibility of me getting just something to help me sleep at night etc. and she said – **all you need my dear is a hug**, and that's what she did. Gave me a hug. I came out without anything."*

And that GPs are **open to alternatives.**

> *"I refused point blank to take it because of the side effects, and she mentioned to me that I would need to take it but I told her that I had a reaction to a tablet similar so I says look, I'm going to try something in the holistic line and if that doesn't work then I'll come back and she said well, in this game,* ***whatever gives you relief from pain do it*** *so I found that was positive."*
>
> *"I do find the* ***younger ones*** *[GPs] that I've experienced since Covid they've actually been more like* ***"no, wait we are open to talking therapy****" whereas any of the older ones are just nah, they're too behind the times, they need updated, they need trained."*

There was a perception in the community that people are becoming **reliant** on medication because there is no other route, and most people can't afford to get private help.

> *"Most people* ***can't afford to go private****; most people can't afford when their mental health is not right to go and get a therapist and pay £80 a session and I think the reason why people are getting so reliant on medicine, we have no other route."*

This reliance on medication was echoed by a GP.

> *"It's money. People get sick because they haven't enough money, they're not getting paid enough to feed their kids, they're stressed out because they literally do not have enough money to get back from one week to the next. There're mammies skipping their breakfast so they can give breakfast to their children. it's bonkers. How would you not be depressed and anxious and have back pain and headaches and a million other symptoms if every day looks like that to you.* ***And then all we have is a packet of fluoxetine and how's that going to fix it for them? But that's all we've got."***

Another HSC participant emphasised the need for alternatives.

> *"They [the people we work with] just don't feel as if they need them {medication],* ***they need that social aspect of it,*** *so that's where [social prescribing organisation] would come in and try to reduce that intake as well so they're not prescribed antidepressants anymore because they just simply don't want to be taking it as well."*

Community participants commented that other HSC staff could give reviews.

> *"A pharmacist outside the pharmacy situation rather than dispensing somebody doing reviews, just medication reviews because if the GPs don't have the time to do it* ***somebody needs to do it*** *because you quoted the figures of the high number of errors in medicine. We need somebody to be looking at that and there doesn't seem to be."*

4.5.6: Barriers to involvement in decisions

Patient confidence

Community participants spoke about the barriers to getting more involved in decisions about their medication. Many **lack the confidence**,

> *"It just seems that if you haven't got the ability, you've got to really be assertive, haven't you? You've got to be looking after your own needs with the GP otherwise things don't get addressed and I feel so sorry for particularly **vulnerable people** who haven't got anybody."*

Participants described as they have got older, they have become more assertive and gave examples of things that they do to **help** themselves in appointments.

> *"I would consider myself fairly well-educated, but I would find maybe dealing with new consultants a bit **intimidating** but what I try to do, and it's only in latter years I've done this, I would **write out a list of questions and queries** that I have before I go in so that I'm not flummoxed halfway through the consultation and that I can tick them off and say that's been answered, that's been answers."*

Hard to question healthcare professionals

Many of the community participants commented it is **hard to question** the doctor

> *"I wouldn't question, it was just **the way you were reared**, you didn't question doctors, you just done what you were told."*
>
> *"Because the public **just do as they're told** because those are doctors telling them, and when a doctor tells you something it's really hard to challenge that because they are the doctor."*

And even for those with professional careers find it difficult to challenge the doctor's opinion.

> *"I was told that I had an underactive thyroid, I was handed a prescription and I was told oh, you must get your contraception sorted out because we don't want you getting pregnant... even as a professional [senior executive role], when a GP says that to you, that's your GP talking and **we're all guilty of going okay, that's fine.**"*

And that **unless you push** the doctor, they will not give you the opportunity to be involved.

> *"They [doctors] speak over you. If you're not big enough to say to yourself, who does he think he's talking to, **if you don't speak back to him...**don't say something to him...he'll speak over."*
>
> *"I just feel like they totally just **brush off everything you say,** they talk down to you especially if you're a younger person and you're trying to talk to them about your child who you know and they maybe only know over telephone calls, they're just completely **patronising** to the stage where you're just like I'm just done with this now and just cut them off, it's **not worth it**."*

Community participants expressed they would like a **joint approach.**

> *"The doctor is the expert after all, so you go to the doctor for an expert opinion and maybe expert intervention if you need it but to me, it should be a joint approach as in **I feel you need***

> ***this, how do you feel about it?*** *And then look, you're on this, that and the other, perhaps it's not a good idea to give you this at the minute but we could do X, Y and Z to allow you to get on with it."*
>
> *"They should tell you by the way, this might happen, this might happen and* ***then we should be able to decide ourselves*** *if we even want to proceed with taking it but we've given so must trust for so many years that we've just been like ah well a doctor give it to me so it must be good when it's nearly just as bad."*

The paternalistic approach to medicine was recognised by the HSC participants, whereby some people were **happy for their healthcare professionals to make decisions** on their behalf,

> *"So paternalistic patient centred care is okay if I don't assume it and I ask you. So, a lot of yes, the population they are of that mindset, I'm quite happy for you to make that decision,* ***I'm too tired, I've lived my life,*** *you make that decision. And that's perfectly okay but* ***we've got to ask the question*** *and we've got to get the answer…So, once I ask you do you want me to make that decision for you then that becomes again, shared decision because you're allowed to do that. Again, I'm taking your wishes and preferences into consideration."*

Fearful of outcome

A few community participants spoke of their concerns about being more involved in decisions about their medication. There was a fear of **authority** and what would happen as a result.

> *"I would be fearful of the outcome of what I would say, like I would be fearful if I was to speak up to my GP would they* ***discharge me from the practice****. I would be fearful that they are very quick to go oh, she's questioning things, what about her mental health, what about her child. You do fear speaking back to people of authority because of the fact that they do have a* ***bit of a leverage over you****."*

HSC participants were aware that some may not want to be involved in decisions as they do not want their medication to **change.**

> *"They're misusing their medication but especially anybody that would have like an addiction, so therefore they don't want us seeing that, you know, so they wouldn't want us touching their medication, they want to keep that to themselves so they* ***can take it whenever*** *they want it rather than if they actually need it…they want to just pop the pills. Sometimes I think that would be a contributing factor to why they don't want us involved in their medication or wouldn't have that discussion that they've done something just in case."*

Time

There was recognition from community participants that GPs have a **heavy workload** and may not have time to give medication reviews.

> *"It's having the time to go away and think about it and follow it up, that wouldn't happen because that would mean* ***another appointment or another phone call,*** *they need [GPs] that wrapped up within ten minutes, that decision made."*

> *"If you phoned up the GP and said I'd like a medication review**, not a hope in hell** have you got of making an appointment."*

Time limits for GPs and pharmacists were recognised by HSC participants,

> *"I understand my [social worker] appointments are 40 minutes, a GPs are ten minutes so it must be very, very hard for a GP to actually go through all that in that **such short space of time.**"*
>
> *"I think a big issue in this is time. So, it's time with the doctor and time with the pharmacist. Pharmacies are **fantastically busy** and they've a limited amount of time."*

4.5.7 Enablers to involvement in decisions

Patient relationship with HSC

Participants spoke about what their experiences of being involved in making decisions about medication and what they felt where the enablers to the conversations.

Being **approachable/understanding/non-critical**

> *"He [GP] was like – I completely understand because I said to him, I don't want Social Services thinking that I can't manage with my kids and he said they're not going to think that, and **I felt like I could open up to him** because of the way he approached me."*
>
> *"I think it depends on your relationship with the person as well because [family member] is under two consultants and I would say I find **one much more approachable and much more understanding than the other.**"*
>
> *"Even currently like I'm going to need to go back on medication, I was took off it when I was pregnant obviously, I know I need to go back on medication, but I don't want to go to my doctor because of the response he's going to have. **I know he's going to be rude.**"*

Trust and reassurance

> *"They ask what's going on with you. They give you what you need and **reassure you like it's a normal thing**, don't worry."*

HSC participants explained that **building relationships** was key to getting people to make decisions about their medication.

> *"I'm thinking in particular of patients who are having chemotherapy and they come out with the bag of stuff and they have maybe anti-sickness medication to take for four days and some of them will say well, I don't feel sick, I don't think I'll take that...but you can have a conversation with them and when you **get to know them better they tend to listen.**"*

And finding out **what matters to them**

> *"what's going to make a difference to you today, I'm here to talk about the medicines but I have no agenda at all, **so what's going to matter to you?** I think people often think oh wow, you know, or just even... but it is actually allowing them and saying what works for you, would*

> *you like to take all your medicine in the morning, what about moving it to lunch time. The old twice a day is a standard thing."*

And **knowing more about their lives**

> *"And looking at medications, doing a bit of watchful waiting and then looking at the whole lifestyle and how it really impacts your mental health and then a lot of social prescribing, all the different support services there is around the community. You do have to try and **work with somebody**, have that discussion, talk about what their kind of feelings are about medication, what their thoughts are."*

And being approachable and using **humour**

> *"I often find people get; they can maybe get a bit embarrassed about the names because they're not that easy to say. **I always make that into a bit of a joke** when....I always say I don't really care how you say it, with my accent I'm not going to tell anybody how to pronounce anything and **they always just laugh**... it really doesn't matter, just get to recognise it, just get familiar with that name because let's be honest, they're not that easy."*

Patient knowledge/understanding – health literacy

People having knowledge and understanding of the medication that they are on, why they're taking it and how it will benefit them helps the decision-making process.

Community participants explained,

> *"It is all about, the doctor that you get. There's a doctor who is very good and she will not overmedicate you at all so she'll get a text message through, look at this, read this, **see how you feel about it**, an alternative route so not to medicate you and then if you do still feel like you need the medication come back to me and we'll go down that route but she's very good in that she'll not just give you something so that you'll go away, she wants to get to the route of it and then see."*
>
> *"It's about that **accessibility of the decision-making process**, it's about the information being shared in such a way that the individual understands because quite often it's not. You've got this, here's these tablets, go away. As opposed to this is how it will impact you and what we'll do is we'll do a wee follow-up appointment, somebody in the who can talk you through."*
>
> *"But when they prescribe them, **you need that knowledge**. Or it is long term and that's okay but an agreement as to how to manage. I mean are you going to be on this medication 'til you're 90 or why do you need it and how long do you think you might need it for and where, you know."*

In the HSC focus groups they described how when they explained medication to patients, they were **more receptive** to taking it as prescribed.

> *"If you've got a woman that wants contraception and she's not sure what she wants you have, it's a very long consult because there's an awful lot of methods of contraception out there. And we send linked information through SMS via phone so you can chat that woman through all the methods...that's a huge amount of information and we have a ten-minute consultation so*

> *what I tend to do is send them the link for a patient friendly app which they can click through every method that's out there and* ***have a read about it in their own time.****"*
>
> *"A lot of people come in, "I'm not taking your medication, I don't want it, don't be giving me your pills" and maybe they have anxiety or depression.* ***No one has actually ever sat down and just explained*** *how they work and how you can come off them and there's a way of coming off them and how long to take them for and how they're not going to do everything, they're going to do about 30-40% and it's the psychotherapy and the talking therapies and the looking after yourself that's going to help as well."*
>
> *"If you're starting people on preventative drugs like statins you can show them the little* ***nomogram****, so it's a little 100 person diagram and it shows them if 100 people started this drug today after 10 years this number would have had a heart attack, stroke or vascular event who weren't on a statin and this is the number who, if they were on a statin would have it. So, it has prevented these numbers. And these are the people who were on a statin but had it anyway because you can't prevent everything."*

Joint approach / being supported to make decisions

Being supported to make decisions was an enabler for community participants.

> *"I think it's just feeling in control of yourself. I just don't feel…I feel that I'm not in control of my own wellbeing because I'm not really being supported to do so, you know, to be in control."*

This was echoed by HSC participants,

> *"I think you would have people taking their medication more effectively* ***if they're informed on it every stage*** *of the way, information for clients for them to be in charge of their own health care, not in charge of but they have more control."*
>
> *"There has to be that sort of* ***engagement, education of it's a continuum****…there's different stages and equally, the end stage might be look, we can't help you anymore here, we have to refer you on."*
>
> *"I look at things and say if somebody has capacity and somebody is making an informed decision it might not be what I think is a good decision but if I give them all the information and at the end of the day they say – I don't want to take that then what I do is I feed that back or try other alternatives or say look,* ***why don't we try this.****"*

A participant who supported people with learning disabilities explained

> *"We do support them to attend but they're given wee* ***prompts*** *and stuff if they can talk for themselves, they may not know all the information but at least they'd be able to talk to the GP about how they're feeling, that kind of way and then the support staff would* ***know their background and history*** *etc. and be able to add on what is necessary but we do have a couple of clients that can speak up on how they're feeling and if they would like to take the tablets or a new tablet or a new dosage."*

HSC working together

Community participants gave examples of different HSC workers having expertise in certain areas, and the benefit of them working collaboratively.

One community participant was also a nurse.

> *"When I worked with Marie Curie, the GPs referred all the time to the Macmillan Nurse Specialists and there **wasn't a thing that they didn't know about medication**. What worked with what and what worked against what. And you know, when you have a specialist time like that, they should be made use of because of the knowledge that they have. And I mean I think now as time goes on the **GPs would begin to appreciate that and refer to them most of the time** but I think we **shouldn't be sitting on our high horse** and we should be referring to these specialist teams because they're in the know and they know the latest and they know how little works for you know, instead of giving large doses, maybe if you gave 10 mgs less it has the same effect. So, I think we should be referring to specialist people like that."*

Another community participant explained their frustrations that their **counsellor, who knows them better than their doctor, can't help** with decisions about their medication because they aren't medically trained,

> *"I know the girl that's doing my therapy better than I know anybody I've ever dealt with, but she can't alter anything in my life because she's just a counsellor, she's not medically qualified, they call it, even for filling out forms. You've to get your GP to fill this. **My GP doesn't know shit about my PTSD [Post-Traumatic Stress Disorder]**. My counsellor spent the last year getting to know my PTSD intimately but no, not qualified to even fill in a form. That's ridiculous because my doctor had to phone me and say – what would you like me to put down on this form because I didn't know anything about your PTSD."*

And recognition was given to the role of carers.

> *"I suppose that's why it's so important that we make use of the information that the ordinary carers going in, not even specialist carers because **they're in maybe two or three times a day** and therefore we should take recognition of the changes they're making."*

Some community participants had positive experiences of different HSC staff working together.

> *"Because I've got so many conditions wrong with me, **I have numerous hospitals let alone doctors** looking after me, I have gone to my GP and this is years ago, and said look, I want a central person that is responsible for me and it was agreed that the [name removed] unit would be that central point, that the GP then wouldn't prescribe anything without her talking to the unit."*
>
> *"Because of my illness, the effects of it lasted a year or more, they wanted me to take an antibiotic from September to May to protect me but that was one of the ones that I can't take, so **that was a conversation I had to have both with my doctor and my consultant** whether to take that or not and we decided then no, because it was better than being sick all the time."*

A nurse and social worker described their roles in helping with decision making about medication by working with other healthcare professionals,

> *"I can't diagnose, all I can do is recognise because my background is as a nurse. But* ***talking to the doctor about the assessment and what my recommendations are*** *and it's having that kind of discussion and then discussing that with the patient as well."*
>
> *"I can't advise people on medications because I'm a social worker rather than a medic but* ***I work really closely with the practice pharmacist*** *and quite often if I identify someone who is really vulnerable in the community the pharmacist will do a* **one to one review with them** *but I'll do a wee bit of prep work with them around what it is you're taking, why you don't want to take that."*

Summary: People being involved in decisions about medication

Experiences around making decisions about medication were varied. It was clear that people can see the benefits, and most would like to be given the opportunity to be more involved in making decisions about their medication.

- Positive experiences of being involved in decisions about medication included speaking to healthcare professionals about issues with their medication and working together to change it to something more suitable; medication being fully explained and being given the opportunity to make their own decisions.
- Negative experiences of being involved in decisions included feeling their opinions were not listened to; medication being prescribed that would not address their issue; being told they must take a medication and having limited opportunity to discuss medication, other options and exit plans for coming off medication.
- People would like to be offered non-pharmacological alternatives to medication and are open to holistic approaches such as social prescribing and community programmes.
- Some people said they had never had a medicine review. They were welcomed to reduce or change the medication they were taking.
- Barriers to being involved in making decisions about their own medication included:
    - lacking the confidence to question a doctor.
    - fear of authority and what would happen as a result.
    - lack of access to GP appointments.
    - short appointment times.
- Enablers to being involved in making decisions about their own medication included:
    - health and social care staff directly asking people their views.
    - staff who are approachable, understanding, and non-critical
    - staff providing a personalised approach and finding out what matters to the patient.
    - staff helping people learn more about their medication.

4.6 Theme 5: Health and Social Care (HSC)

In the focus groups, participants were not directly asked about HSC systems, however discussions naturally emerged which are relevant to medication safety. It is a key theme of the research and the findings are presented in this section of the report.

4.6.1: HSC pressures

In both the community and health and care focus groups there was acknowledgement of the pressures that HSC are currently facing

> *"It's very **hard to get a doctor** nowadays… it's not their fault, there are shortages"*

In the HSC focus groups there was discussion around how **limited time and resources** impact upon medication safety.

> *"It's the time, it [medication safety] needs a dedicated focus and we've deployed **a very scarce resource**"*

These time pressure mean medicines labels aren't clear.

> *"it's just they're in the habit I think of putting 'one daily'…but that's just going to take time, and everybody is under pressure with time, and you can just see how **something like that just slips through**. And it's not considered to be important but actually, I think it's really important".*

Staffing shortages mean people aren't getting the support in home they need for medicines.

> *"In some cases, we have **problems getting carers for night-time calls**…or four times a day if someone is on a medication four times a day… and therefore, pharmacists have to have a look and see if we have to review how often that medication is given or can it be given at a different time or whatever".*
>
> ***"Care packages are really hard to get at the minute**, to the point now nearly that if families are really struggling and trying to push direct payments so that they have some form of support".*

4.6.2: Communication between Health and Social Care staff

General Practitioners (GPs) and pharmacists

In the community focus groups, participants discussed getting conflicting information and advice about their medication from different HSC professionals.

They provided examples of pharmacists engaging with GPs about prescriptions.

> *"I developed cellulitis so I had to get an antibiotic and the antibiotic didn't clear it so I went back to my GP and got a second different antibiotic and a couple of days later I was talking to the pharmacist and she said **the GP shouldn't have done that**, the GP should have kept you on that first antibiotic for a further seven days rather than change the antibiotic…certainly as far as the pharmacist was concerned, it wasn't good practice".*

However, one participant said their GP wouldn't engage with the pharmacist.

> *"One of the doctors in my town wouldn't talk to the pharmacist about it. They were quite **adamant** that what they were saying was right".*

One of the HSC staff emphasised the importance of having a **set pharmacist** so they can do extra checks on a patient's medication.

> *"We tried to get patients on complicated drug regimes to buy into one pharmacy and stick with it…like maybe they're on warfarin and they go off with a sore toe and **they see the doctor on call who doesn't realise** they're on warfarin and gives them a drug that will interact, and they could bleed out. If they always go back to the same pharmacy the **pharmacist is your stop gap there**, they will ensure that they don't get prescribed something that's going to potentially kill them".*

GPs, hospital doctors and consultants

Community participants gave their experiences of receiving conflicting opinions on medication from their GP and hospital doctors and consultants which can be confusing.

> *"If a consultant says **you need to** be on short take, long take, one of those opiate pain reliefs for a week… and your GP says well no, **we don't allow that** sort of medication in the community, there's a consultant saying you can have that for a week but your GP is saying no, you can't, you need to be in pain for that week"*
>
> *"My daughter is on diazepam…she gets seven a month because the GP does not agree with giving diazepam yet the consultant in the mental health team is prescribing the diazepam, **but the GP doesn't like to give it** because it's not their policy … Which one is right, and which one is wrong".*
>
> *"Hers [daughters' medication] was changed, so she's only getting reviewed, this is her first time in a year and she's on that medication and she is getting reviewed now in two weeks' time, but the GP gets a letter from the consultant and **until he gets that letter from that consultant,** he cannot change that medication".*

One participant noted that their GP didn't ask what other medication they may have been prescribed from other health care providers.

> *"You go and see your GP, he's put you on a medication. I'm seeing two or three different consultants at the minute. They're putting me on new medication. My GP **doesn't even ask questions**".*

Community participants also described conflicts between healthcare professionals due to the **affordability** of medicines.

> *"I was told to take a specific tablet for my blood pressure because I seemed to be allergic to a lot of the other ones, so he gave me a prescription to give to my doctor which I did, and then the hospital called me up in three months for a review… he just looked and said what are those for? And I said, well that's what you prescribed. He said, **indeed I did not**, I didn't want you on them… I was thrown out of the room for a while and the shouts of him was terrible and I could*

> *hear the conversation from both of them and my doctor said – **well, it's a penny a month more for them and I'm not affording that on my budget".***

4.6.3: Policies and procedures

In the focus groups with HSC there were discussions around medication safety policies and procedures and how they are implemented.

Domiciliary care workers explained that they only administer medicine in a blister pack and there are clear policies and procedures for administering medicines, they have to attend regular training and document what they do.

> *"We're [domiciliary care organisation] quite robust that way, especially with the medication and training…all our staff get **refreshers** training face to face, and they get **yearly** online training as well".*
>
> *"We [domiciliary care organisation] have to have **everything documented**… and you have your RQI inspections etc. too, they'll highlight that, what have you done following this medication incident, so you have to have all that evidence there".*

They also described what they do if a staff member becomes aware that a client has not taken their medication as prescribed. If there is health concern the first point of call is the GP or the doctor

> *"All our ground staff are very aware of the protocol because **we can't take the chance with medication**, especially if we don't know that the client's overdosed on it, or if there's a sedative in it or if they've had a reaction because they've maybe took their husband or their wife's medication. So yeah, the **first point of call would be the out of hours GP or the doctor straight away**".*

They also have a manager on call that they can report to and seek advice from

> *"If we feel that the clients aren't coping with their medication then we always **link in with the care manager**, we always **try and reduce that risk of anything happening** in relation to them taking more medication than they should or taking the wrong medication".*

HSC participants explained policies don't always work across organisations,

> *"Say an antibiotic is written up then that's another referral for district nursing because a lot of pharmacies will not add the antibiotic into the blister pack. So, you have to go out and write that there up for the carers to administer the antibiotic, but if you're sitting with three things and one could be an inhaler and one could be a cream. And something I came up against recently was an emollient into the water to wash the patient, but private care agencies said no, that they couldn't because it was more than three things were written outside the medication… carers refused, they said no, **it's outside their policy**".*

Even within one HSC Trust where the same policy applied, participants noticed the **implementation** can be different in different areas.

> *"P1: The social worker would usually oversee the blister pack and introduction of that, and then district nursing would do creams and anything that's not in the blister pack.*

> *P2: In my area and that's not the case.*
>
> *P1* ***We're all doing something different****, aren't we… and we're all working under the same policy".*

Implementation is more difficult when **direct payment** carers are used - a social worker described how monies are monitored, but medication is not,

> *"I know from all my Trust carers I'm always updating medication policies as part of reviews…with direct payment carers you just trust,* ***we police check people, the payments are going in and we're not actually monitoring the medication, we're monitoring the monies****. And I've actually got a direct payment lady at the minute who is very vulnerable, and she manages her own account and I have to go…to speak to her tomorrow about her private direct payment carers to make sure they have been trained, are they using the manual handler procedures correctly to avoid further tears to her".*

There were some concerns from **social workers** that they are **not medically trained**, and it can therefore be difficult for them to support people with medication.

> *"I just feel it doesn't sit well with me as a social worker because I'm not medically trained, and* ***my awareness*** *of what medications are for or dosages etc…it's not up to us to be saying what its [medication] is for and what's not…I feel it's a* ***very precarious area at the minute****, especially from my background as a social worker, and we have raised it up several times and it's one of the things that my team wanted me to add in, they just, none of us feel comfortable in doing it, it just* ***leaves room for errors to be made****"*
>
> *"We are taking guidance mostly from the care providers that are going in maybe in the morning and the client will say oh, I was at the doctors yesterday or it might be reported that client mobility has went down and they have an infection so an antibiotic has been prescribed and then they'd mentioned it on the first care call of the morning and then they'll contact us and ask us then to do a* ***proforma out on it****, and then it's trying to source what's actually said on it, dosages and all, that's why I think our team is very reluctant to do it because it's* ***quite dangerous practise*** *that I feel from a social work point of view"*
>
> *"The other thing for us is in our Trust we have a medication policy for carers to administer the blister packs and carers can only administer tablets via blister pack. But if there's a new medication started and it's not in the blister pack then it could sit there for a week before somebody alerts us to put in an amendment to that medication policy to say please take this separately until we get it in the blister pack next week. So, there can be some problems with that and if district nursing aren't involved in a house or if carers haven't informed us that there's an extra medicine that isn't in the blister pack then it could sit before we're informed"*
>
> ***"****I don't feel safe doing medication policies in my job, and* ***I'm very clear with my management*** *about that. We're lucky enough to have blister packs and that's a godsend because you can write on it as per blister pack instructions when it comes to the add-ons, that's where it's difficult".*

4.6.4: Transitions of care

Participants raised some concerns about medication safety with transitions of care.

Service to service

In a community focus group, a parent explained the difficulty their child experienced in accessing mental health medication when transitioning **between child and adult services**:

> *"We moved from CAMHS... she actually was...settled and taking the antidepressant and antipsychotic medication and then there was a wait list to get into adult services and **that was it, that was the end of the medication**...because there was that waiting list for the transition into the mental health team".*

Home to hospital

Some participants described the hospital staff trying to give them their prescribed medication incorrectly, but the patient **knew themselves** when they were meant to take it.

> *"When I've been in a hospital I've had major discussions, shall we say, with the nursing staff who tried to give me after I've had either my breakfast or before my dinner, my food at night and I said no, I am no to take them within a certain amount of hours but **yet they still give them to me.** Unfortunately, I think it's down to the shortness of nursing staff in the hospitals".*

> *"They [hospital] had tried to change my blood pressure medication but I had said to them, you need to contact the GP, I am slightly allergic to a certain type of blood pressure tablet and **before you give it to me can you please check,** which they did".*

Hospital to home

In the community, participants gave examples of issues with medication safety with the move from hospital to home as medication has **changed.**

> *"The lad I care for, he had a hospital stay, obviously they looked at all his medications to see if anything needed changed and they kept on what he was on but they added two extras so when he got out of hospital I went to the GP with him because **the hospital didn't really get time to explain** what they were for and why".*

In the HSC focus groups, concerns about medication safety when moving from hospital to home were raised. People can be **confused** about their medication when they leave hospital.

> *"They're absolutely just completely confused...**Unless you are in that house** to do something to say well no, look at the discharge letter here, no this is what you should be taking...and they don't know what they should be taking...and you have to spend the time just to... **go through the discharge letter with them**".*

This can be especially difficult if the individual has **no support** in their home post-discharge:

> *"And then as you say as well, there will be people coming out of hospital with a big bag of medicines that won't have a district nurse or a social worker going into them too and then you **wonder what's happening to them**".*

And as their medication may **look different** from the hospital pharmacy compared to the community pharmacy

> *"Because everything out of hospital **could be all in white boxes with the label on it and they all look the same** and not the same as what they were used to in their own packs from their own pharmacy. So yeah, there's probably a lot of people not having someone go in. You see that post discharge".*

They also noted that is important for GPs or GP practice-based pharmacists to **update the community pharmacy** on a person's medication changes post-hospital so that people get the correct medication.

> *"Otherwise, what happens is the pharmacy **doles out their regular monthly dose** set box **without realising** there's been a change in the interim".*

4.6.5: Systems

Perceptions of finances

Community participants spoke about a perception of medications being prescribed due to **financial incentives** for HSC and pharmaceutical companies.

> *" These pharmaceutical companies are dishing out these medications which might cover something but disastrous to something else but they're getting them out because it's **money**…"*
>
> *"**The practices get money for distributing**…for statins**…£25 per person** because I did a lot of research, for statins".*

There was also a perception that medicines are being prescribed because of their associated **costs and profits**,

> *"These people that actually make the drugs. …**it's all profit**, all profit all the time".*
>
> *"If you find that a tablet you get was helping you…the tablet you get now isn't as good as the one you were getting, and I think they're **giving you a cheaper tablet**. That's the one I need cos that's the one helped me, but you'll not necessarily get it".*
>
> *"I'm not talking for myself, I have an autistic son and he was getting tablets for things but then they give him, as I thought, a weaker tablet and they weren't helping him and we had to sort of demand off the doctor, could he not get those, but **they seemed reluctant to give the tablet because I found out they were a dearer tablet**".*

And that doctor surgeries are **run like businesses** and the personal side of healthcare no longer exists and is more about money.

> *"Doctors are running a business now because they have managers, they're not medical, they're business managers and they're running a budget. We're just the client, **we're not a person anymore**".*

Responsibility

In the community focus groups, people felt it **wasn’t always clear** where the responsibility lies for medication safety.

A community participant noted that there is no healthcare professional responsible for **checking on medication as a whole:**

> *“There’s no ownership of the information I think, you know, somebody there is going to four or five consultants, they’re all looking at their own specialty. The GP is being advised by the specialist but is there anyone really taking a total* ***overview of all meds****?”*

A social worker spoke about how she flagged concerns about one of her clients with an alcohol addiction being prescribed Diazepam and nothing changed.

> *"I have flagged it on six or seven occasions and wrote it in her notes that I wanted it looked at, went to the pharmacists who actually did do something about it but still has been described diazepam with an alcohol addiction and shouldn’t be having diazepam at all… Nobody else was referred through to the community team, social workers aren’t pharmacies so they can't do anything about it,* ***it’s not in their remit****”.*

Silo working

Personalised labelling could help improve medication safety, however, one pharmacist explained that this could **increase their already busy workload** and some health care professionals will **not see the wider benefits** for patients.

> *“We have probably about over 200 independent GP practices* ***all making up their own rules****. “I’m not going to sync anything for someone in the care home because guess what, to churn out a box of 100 goes ‘click’. To sync for a person because she only needs 64 this month just to get her back on track…I have to go in, retype, what takes one click then turns into five steps” …. And that’s siloed working.* ***You’re on your own****”.*

Access to records

Not all healthcare professionals have access to the same information about their patients, and pharmacists do not have access to electronic records.

> *“The system is* ***not built to support you as the healthcare professional*** *because they said well, I’ve asked before, but they don’t have the information and they don’t know and it’s that lack of access to electronic records which can drive harm as well…* ***you’re navigating this individual blindfolded****… It’s not black and white in front of you but you have to predict that is a potential outcome of harm”.*

Medicine Supply

HSC participants discussed medicines **shortages** and the impact they can have on medication safety.

> *“It’s not infrequent, you do a script for a patient, they bring it to the pharmacy, the pharmacy hasn’t got it and nor can they get it, and this is happening with loads of drugs, everything from*

> *creams…**the patient has to tramp round a million pharmacies** and some of them just give up".*

Some HSC staff **work collaboratively** with others to try and get medication due to shortages:

> *"Like yesterday I was out with a couple, and they were having problems with supply, they couldn't actually get supply from their chemist, **so I worked with their chemist** and I'm just waiting to hear back from the GP practice".*

Synchronisation means that medicines refill dates can be aligned for people taking two or more medicines at the same time. Several HSC participants discussed the benefits of medicine synchronisation.

> *"**Synchronisation and waste is a symptom of our poorly designed system**…if we had a service like our emergency supply service where we were allowed to synchronise medicine…We would be onto a winner for the patients, but we're not allowed to use the emergency supply service to synchronise services".*
>
> *"One of the learnings from the pandemic where we would free up the waste in the system, and free up time because you're not sitting on the phone trying to get through to synchronise, you've sorted that synchronisation…so it's that culture of **what can take me five minutes now just to take this step that will save us 15 and that's the time that will allow you to have that conversation**".*

It was discussed that **manufacturer issues** can make synchronisation difficult:

> *"But the manufacturers don't make it easy for synchronising because some consider a month's supply 30 and others consider it as 28. So, I've got somebody synchronised beautifully and **then the 30 started creeping in**".*
>
> *"The other day I nearly went off my head, a medicine comes in 10 mls and 50 mls and to get a month you need 56 mls like **they're taking the piss out of us**".*

Overall system issues

A comment was made regarding the difficulty the community faces in **using** the healthcare system:

> *"I think that is our biggest challenge, that this is a dynamic continuum of change, and **our system is not built to address that continuum**… we have individuals in their own home trying to navigate this landscape where the **system should navigate the individual**, it's all the reverse psychology but the simple first step".*

Summary: Health and Social Care

Participants were not directly asked about health and social care systems, understandably the health system naturally arose in discussions on the topic of medicine use and safety.

- Health and social care staff were aware of the differences in their knowledge regarding medication practices and the benefit of learning from each other.
- Silo working in health and social care can create confusion for people in the community.
- There can be a disjointed approach to applying policies and procedures for medication, both across and within Health and Social Care Trust (HSCT) area boundaries e.g., the administration of blister packs across HSCT areas.
- Social workers highlighted that as they are not medically trained, their roles and responsibilities for supporting medication safety are not always clear.
- Medicine shortages and supply can impact medication routines.
- Some healthcare professionals spoke of the benefits of synchronising medicines (refill once a month).
- Medication can change during transitions of care, and this can be confusing for patients.
- Some transitions of care may not be meeting the needs of specific target groups e.g., young people transitioning to adult services.
- Health and social care staff value having their voice heard, sharing their experiences, and learning from others on medication safety issues and practices.

4.7 Theme 6: Know, Check, Ask

The 'Know, Check, Ask' campaign was developed by HSC to highlight and increase understanding and awareness about the importance of using medication safely. Resources were developed for both the public and healthcare staff including posters, video animations, and a 'My Medicines List' for people in the community to note information about their medication[i]. The campaign had only been launched through the Living Well campaign in pharmacies when the focus groups took place. Participants were asked for their initial thoughts on the Know, Check, Ask campaign and its resources. This was the first time most community participants had heard of the campaign or seen the leaflet. HSC staff had more awareness of the campaign, but had little experience of practising Know, Check, Ask as it had just launched.

4.7.1: Usability of Know, Check, Ask as an individual

Knowing your medication

The community participants discussed benefits of using Know, Check, Ask which included an **increased knowledge and understanding** of the purpose of medication,

> *"I would say a lot of people would struggle saying* ***"I'm on this" but "I don't know why" …****they would tell you they were allergic to celery, but they don't know what the blue tablet is they take in the morning".*
>
> *"Sometimes you're prescribed stuff and you don't know why, so* ***if you know why you're taking it it's half the battle".***

As well as being able to **remember** what medication they are taking,

> *"I actually quite like it. I never remember names. I do know what most of them are for, but do you know the way sometimes you're like* ***what's that one again****".*

Health and Social Care staff also discussed the benefit of increased knowledge and understanding,

> *"We have them new My Medication List leaflets to give out, so I would give them out a lot now to our patients just in terms of* ***more understanding*** *of the tablets that they're on and having a list of them and kind of just being more aware."*
>
> *"it's a very good campaign. I hate when people phone up and say* ***will you give me the blue ones, the pink ones and the white ones and they don't even know what it's for****!"*

This was particularly emphasised by Health and Social Care staff for individuals who may **lack capacity** to understand what medication they take,

> *"The one place this would really make a difference is…****elderly patient*** *hospital discharges… they hardly knew what they were on before they went in with their frail fall but they sure as hell don't know what they're on when they come out and* ***everything has been changed****".*

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[i] All resources for the community and health and social care staff can be found here: https://online.hscni.net/our-work/pharmacy-and-medicines-management/medication-safety/know-check-ask/

Onus on individual

People in the community expressed discontent that the Know, Check, Ask campaign was giving **responsibility back to the patient** rather than HSC staff.

> *"It's putting the ownership back onto the patient".*

And in one focus group when the meaning of 'Check' was explained, all participants felt that to **'check'** medication is not their responsibility,

> *"What's the check bit then? (P1) … Check to see you have the right amount of medication, and how you're meant to take it and understand why you're meant to take it. (P2) … **But that's not their responsibility!** (All)"*

Health and Social Care staff **did not discuss this** as an issue.

Discussing medication with healthcare professionals

An example was given from a person in the community about **successfully practising 'Know, Check, Ask'** when being prescribed a new medication,

> *"I got put on thyroxine recently for your thyroid I think, and I just asked him [community pharmacist], "**when do I take this, how often do I take this and do I take it forever**".*

Practising Know, Check, Ask was described by Health and Social Care staff as a way for **relationships to be built and improved** between the community and healthcare professionals,

> *"…allowing people to be more open and…more informed and say "oh, I didn't know that was for my heart!" … So, it's maybe a great way of that trust and relationship…and **allow that more open informed conversation**, and then they come and say – I don't really understand this".*

4.7.2 Usability of Know, Check, Ask as a healthcare professional

Explaining medication to the community

Health and Social Care staff discussed the benefit in using Know, Check, Ask to **check understanding and knowledge** of taking medication safely and correctly,

> *"People would be so used to getting a tablet, "I've taken that tablet for so many years" but they might not realise they have to take it half an hour before food or at a certain time for it to be effective. So, definitely I think the Know, Ask campaign will be really good to check in with people that they **understand what they're taking".***

A healthcare professional working in domiciliary care explained the benefit of **having their own knowledge** of medication to correctly explain it to the individual they care for,

> *"We all know you administer from the blister pack etc. but sometimes they'll say to me what's that tablet for, **I'm not a doctor, I haven't a clue** what it's for and I have to get into Google to see".*

Barriers to practising Know, Check, Ask

A **lack of time** to practise Know Check Ask was voiced as a concern, with a healthcare professional suggesting **resources should be allocated** to address this issue,

> *"The problem I suspect in hospitals is the sheer volume of discharges every day… **they're not even coping** getting their drugs up from pharmacy in time to let them discharge on time but…you would need a **dedicated clinical member of staff** who understood medicines and prescribing to be allocated the task of doing the Know, Ask, Check with discharge."*

A pharmacist commented that the **absence of the Medicine User Review Services** meant there is less opportunity to use Know, Check, Ask

> *"I think that the absence of the medicines user review service is quite significant at the minute because it gave pharmacists **a time to run through** people's medications to Know, Check, Ask. And I think since the service isn't really there anymore it's very difficult for a community pharmacist to have the time to have those conversations with patients".*

Having knowledge as a healthcare professional

Healthcare professionals explained the benefit of knowing the difference between a **normal side effect** and what may need **medical attention,**

> *"…what it's for and the side effects are on it, say they develop a rash or something, some staff with maybe no knowledge of that medication would think **oh my god, there's something seriously wrong here,** whereas a rash or blushing could be part of the side effect".*

And that campaigns like these can be a way to ensure **correct practises** are being followed with medication,

> *"I think it's always good as a fresh reminder for staff, especially whenever they're involved with dispensing as well…It's amazing how time goes by and there's **the odd shortcut or whatever creeps in** and then that becomes bad practise".*

Healthcare records

Difficulties around **healthcare records being different across systems** means that practising Know Check Ask as a healthcare professional can be difficult,

> *"And the other problem is that the ECR [Electronic Care Record] is not always up to date, and that's what we have to rely on authorisation for prescriptions. And it says, the first thing it says in red is please check with another source, this is **not always up to date**, and that's the patient's electronic care record".*

4.7.3: Leaflet tool

The Know Check Ask 'My Medicines List' leaflet was launched in community pharmacies in NI and made available online to the public. This leaflet contains a table for users to note information about their medication such as the name, purpose, side effects, how often/what time it should be taken etc. Participants noted their opinions on the leaflet.

Knowledge of medication

Building overall knowledge of medication was noted by community participants as an advantage of using the leaflet,

> *"I think when you read it over once you'd **be more aware** that you wouldn't really need to look at it every day, you'd say you know what strength they are, what's that for".*

HSC staff noted being able to **refer to the leaflet** as beneficial in explaining medication to people they support,

> *"They wouldn't have a clue what their tablets are for…I think that [leaflet] would come in handy because if they're asking us what's that tablet for **then I can say to them what their tablets are for**".*

And **understanding side effects** to help in carrying out their role,

> *"I think the side effects would be a good thing as well because it would maybe **explain some people's behaviours** after they take their medication as well, if they're tired, it could explain a lot".*

Purpose

Some community participants were unsure of the purpose of the leaflet,

> *"You're writing it down but is it so that if you have an accident somebody knows, **what is the purpose**?"*

A HSC participant explained that **improving prescription labels** on medication by adding more information would **remove the purpose for a Know, Check, Ask leaflet,**

> *"In the pharmacy they'll give you the medication and what dosage and time they've to get it at…but on the actual sheet itself it gives just the **one strip, if they would write on that** that it's actually for hypertension or for irregular heartbeat or whatever…then that would save all that because then everybody knows what the tablet is for".*

Outside the home

Having the leaflet outside the home was discussed as being convenient in multiple focus groups,

> *"You're probably better carrying one of them because that would be handy for…if you were **going away somewhere**".*

Particularly in case of emergencies,

> *"Yes, like I have an implant in my back and I'm not allowed an MRI but **if I was to collapse in the street and they took me in they're not going to know that**. So…I probably should have something like this".*
>
> *I think it's good that people have ownership of their own lists so that if they have to **go to A&E** for something and they say 'well, can you tell us what medication you're on' and you're like 'sugar, what's that one called again'…at least you would have a list".*

While some found the leaflet potentially useful, some noted that they **would not want to carry the leaflet around**, particularly **young people.**

Using the leaflet as a carer

Many community participants voiced the benefits of using the leaflet as a carer to kn**ow what medication the person being cared for is taking,**

> *"I have a nephew who is going off to live on his own but with shared care in Social Services, so I'll be putting his medication into a pot for a week, and I would put that with it … It would be **good for respite**".*

Graphics and visuals

Participants were asked for their opinion of the graphics and layout of the leaflet, with some community participants giving positive feedback,

> *"And it's **not intimidating**…it's **a nice friendly** looking post."*
>
> *"As long as the information is **straight to the point** and doesn't go on for three pages. I like it when it's straight to the point".*

Several community participants **did not like the animation** on the front of the leaflet as they **felt it looked like a child,**

> *"I don't like the leaflet; I **don't like the picture of the child** on it."*
>
> *"The child on the front of it…I mean it's **not really meant to be for children to fill in themselves**, it's meant to be for an adult to fill for their own medication or a child and I just think **it just doesn't present well, to be honest**".*

A popular opinion was that the leaflet was **too large** to carry around,

> *"It's a little bit large that way, if it was a bit you know, smaller, say half size but possibly two, like a booklet but maximum of four little pages it would be **easier to fit into your handbag and especially for gentlemen to fit into their wallets".***

But that some sections of the leaflet were **too small** and **not emphasised enough**, such as the section to note any **allergies**,

> *"The only problem is where you've got the allergy…it's not quite a large enough area. I'm allergic to five medications and it asks you what you're allergic to and how you react. **You can't get all that in there".***

HSC staff gave no notable comments on the graphics and visuals of the leaflet.

Completing the leaflet

Participants **expressed interest** in completing the leaflet and believed it would be beneficial for them,

> *"I think it's great. Oh, I'm going to use it, **as soon as I go home,** I'm going to put all my meds into it".*

But some noted having **no interest** in completing it,

> *"To me this is **just extra stress on top of stress** and people don't have the time for it, to be honest".*

Concern was expressed for those who may **need assistance** to complete the leaflet,

> *"But my mum being able to update it herself**, it had to be somebody that was looking after her like myself.**"*

It was suggested that **support should be available** for people when completing the leaflet,

> *"If they allocated a member of staff to the table beside this for the first while at least to maybe help them do this I think it would take off but unless there's going to be somebody there to help people, not everyone is going to benefit from it because **not everybody can read and write**".*

Healthcare professionals echoed people in the community on this issue, and noted that **timing** may be an issue in providing support to complete the leaflet,

> *"The biggest problem I perceive again, is back to time. No way in **a ten-minute consultation** am I going to be able to sit there with that sheet and **start handwriting in every single drug**. I've got a diabetic that could be on nine different medications…it is going to be fascinating how the data is going to be accurately transcribed…how on earth we're going get the data from our electronic systems onto those pages because **there isn't anybody in here has time for this**, we're two doctors short at the minute, we are really struggling".*

Capacity issues were also acknowledged by healthcare professionals as barriers to being able to complete the leaflet,

> *"I think you'd have to be sure that the person first of all **can read,** and in terms of their **literacy level** and in terms of **understanding** what's on it and obviously it would need to be **jargon free**".*

And that some individuals may need **carers or family members present** when completing the leaflet to help with caring responsibilities, but that **timing may prevent this** from happening,

> *"if it was an elderly patient with the start of cognitive decline you would need their **relative who is the key stakeholder** that's going to order their medicines to be sitting there in the room so that this was done once with the patient and their key carer and it was gone through at that time, I could see that making a material difference if it was possible. The big problem is **manpower in hospitals - nobody has enough**."*

Changes in medication

An issue with the leaflet concerned when prescribed medication is changed, and this **change needing to be reflected** in the leaflet.

> *"My medication changes and sometimes things are taken out and things are put back in and **if that's full then what are you supposed to do**?".*

> *"But it would be **out of date within a fortnight** as well with medication changes all the time".*

Healthcare professionals also noted this as a potential issue with the leaflet, and suggested that something **real time** that could be changed would be beneficial in ensuring **accuracy** of the list,

> *"by the time you would be going to a hospital appointment or something, **that could be changed five times** over by that time, and I think if there was something in real time that you could even **log into an account** or **print something off** that it was the most up to date medication list and dosage, I think just to keep it more accurate".*

4.7.4: Suggested improvements

Electronic Know, Check, Ask tools

Several participants suggested that a **Know, Check, Ask app** should be developed, especially for young people to be able to practise Know, Check, Ask,

> *"The only thing I would say is for younger people you would need to have an app or something. That [leaflet] **would get f**ed out in the corner**."*
>
> *"Like we [young people] do **put everything on our phones".***

And those who **care** for someone, such as parents,

> *"An app would be good that you could **share with another family member** because the likes of my husband that medicates my daughter, he wouldn't know what dosage as in maybe 2.5 mgs blah, blah, if he went to the hospital with my daughter and I wasn't there, **he wouldn't have the first clue!**".*

The **need for a leaflet** was still voiced for those who **do not have access to apps**,

> *"How does that work for an **elderly individual that's on their own**, an app wouldn't work (P1) ... Then it probably needs to be both - **a leaflet and an app maybe** (P2)".*

Summary: Know, Check, Ask

Participants were asked for their initial thoughts on the Know, Check, Ask campaign and its resources. This was the first time most community participants had heard of the campaign or seen its resources. HSC staff had greater awareness of the campaign, but had little experience of practicing Know, Check, Ask as it was a relatively new campaign launched at the same time the focus groups were being held.

- Community participants could see the benefits of understanding and knowing their medication.
- However, the purpose of the campaign and leaflet and how it will help people wasn't always completely clear.
- There was a concern from community participants that the onus of Know, Check, Ask would fall solely on the individual.
- Some people need help to understand their medication and complete the leaflet.
- The practicalities of updating the form after changes to their medication and carrying it were raised, including the potential solution digital forms might bring.
- Time constraints and staff shortages can mean it is more difficult for healthcare professionals to practise Know, Check, Ask with patients and the public.

5. Discussion

This research aimed to discover the social circumstances behind unsafe medication practises and avoidable medication related harm to inform the implementation of the TMSNI plan.

Social Determinants of Health and health literacy

The main theme to emerge was social factors influencing medication safety. Participants were found not to take their medication as prescribed both intentionally (making an active decision) and unintentionally (by forgetting or due to circumstances out of their control). Many social factors contributed to these events, including busy lives, prioritising others' needs, accessing services, social support, work patterns, physical and psychological capabilities, mental health, addictions, income, access to transport, access to healthcare, and social stigma.

Community participants had positive experiences with health and social care staff who provided respectful and compassionate care and understood their social and cultural context, known to be beneficial in maintaining relationships and practising person-centred care[61]. However, some also voiced that social factors were only sometimes considered in their care. This supports the conclusion of a recent systematic review that the relationship between social factors and medication safety warrants more attention from healthcare providers and policy makers.

> *"I haven't taken mine [medication] today because I thought... I can't be trotting out there [to the toilet] every half hour or whatever so i will take it when i go home but the rest of my day is screwed. You do what you can for the circumstances you're in"*
>
> **Community Participant**

Health literacy has been identified as a social determinant of health[31], and it was a dominant theme throughout the findings. Community participants were found to have varying abilities in accessing, understanding, appraising, remembering, and using information about their medication. They also voiced that health and social care staff sometimes presume they have the correct knowledge and understanding to take their medication correctly.

> *"For years I've been taking levothyroxine, only recently found out I should have been taking it half an hour before eating, and since in a week of taking it correctly I feel like a new person."*
>
> **Community Participant**

Health and social care staff also highlighted complex scenarios to communicate with patients, such as educating on the benefits of preventive medicine and addressing concerns around the role of 'Big Pharma' on medication availability. Community participants' health literacy was influenced by many different sources, including friends' and family's experiences, individual's own research, health and social care staff, social media, and stories in the media. These findings reflect recent research by WHO (2022)[3434] which found people rarely make decisions about sustained daily activities or major life issues in isolation; they are influenced through various levels of involvement from other people, including friends, family, people in the community, health workers and other community networks.

> *"I just hear a lot of people, I was listening to other people saying oh I can't take them [prescribed medication], they're no good, they're damaging."*
> **Community Participant**

Community participants discussed methods of accessing information about health, medication and the health and social care system, including online and social media. The conflicting information on these platforms made it hard for participants to know what information was reliable. This reflects a recent report by WHO[62] that shows that while digital technology and social media are powerful tools to disseminate public health information, widespread disinformation can undermine the messages, and confusing and conflicting information makes it difficult for people to know what to believe or what to do for their health. The WHO report also found that providing the public with health information via posters, pamphlets, TV, and radio can be a good starting point, but emphasises that care needs to be taken with the design to suit different abilities and cultural backgrounds. These resources are often more valuable when designed to be discussed among family and friends rather than read by individuals. WHO also noted that health information alone might create health inequities because more educated and resourced people tend to understand better and adopt the recommendations; therefore, it may not lead people to change their daily activities when their social practices, circumstances and environments prevent them from doing so. Therefore, to enable medication safety information and messages to resonate with the public and be acted on successfully, the approach needs to engage with communities and go beyond a traditional health information campaign in social media, TV, posters, and radio. There is a need for a community health literacy programme to cascade reliable and trustworthy information on medication safety among the community that can be discussed among family and friends and adapted to local needs and take social practices and norms into account.

> *"How dangerous this is, it's all the misinformation that we're getting on YouTube or whatever it is…there's nobody here to say look, this is not right, they're scaremongering or whatever. We don't have access to information here to combat these things"*
> **Community participant**

The young people in this study agreed that taking medication is not something they would typically do without help, emphasising that medication safety is a multigenerational concern. Improving medication safety in other settings, such as schools, needs further exploration. Primary schools, for example, can use resources such as the Pharmacy School Programme that discusses age-appropriate health service and medication safety issues. However, such programmes are not compulsory for schools, and such messages are not continued in post-primary schools. There is a need for medication safety messages to be given and reinforced at key points within the life course to build confidence within all generations around medication practices.

Health and social care staff also have a role in improving health literacy. Previous research demonstrates the importance of health and social care staff communicating effectively with patients so they better understand their health and medicines and can make informed decisions[63]. The research findings highlight the need for staff training on health literacy and communication as well as the social determinants of health and health inequalities, how they can impact medication safety and what support may be needed for people to reduce medication harm.

Reporting medication issues and concerns

There were positive and negative experiences of reporting errors and concerns about medication. Many of these experiences were based on interactions and relationships between patients and staff, and knowledge of reporting processes. Consistent with international research[4546], barriers to reporting included fear of consequences of reporting and not knowing the reporting processes or the importance of reporting. Enablers to reporting included understanding the importance, risks, and reporting processes. Addressing any barriers to reporting medication errors can improve peoples' medication safety practises and enable health and social care staff to learn from mistakes and implement preventative measures for the future[48]. Health literacy and person-centred care can play a crucial role in enabling the reporting of medication issues by ensuring that people in the community have the knowledge and confidence to report. This information should therefore be included in the cascading health literacy programme for patients and the public.

> *"At the time my boy was 12 you were afraid to say anything because it would always be the fear of Social Services will now get involved and I already have enough stress factors going on in my life never mind thinking is my child going to be taken from me because I'm having issues with pain medication that you put me on in the first place".*
> **Community participant**

Making decisions about medication

Participants expressed a general openness to being more involved in decisions about their medication. Like reporting errors and concerns, these experiences were based on interactions and relationships between patients and staff and knowledge of shared decision making. Issues of overprescribing due to a lack of shared decision making were raised. Participants highlighted situations where a non-pharmacological alternative may have been more appropriate, or medication use was inappropriate for their specific circumstances and wishes. Many expressed a desire to be offered alternatives to medication or social support alongside a reduction in medication (e.g., social prescribing). A recent review in England by the Department of Health[64] identified ways to reduce overprescribing,

> *"People get sick because they haven't enough money, they're not getting paid enough to feed their kids, they're stressed out because they literally do not have enough money to get back from one week to the next... How would you not be depressed and anxious and have back pain and headaches and a million other symptoms if every day looks like that to you. And then all we have is a packet of fluoxetine and how's that going to fix it for them? But that's all we've got"*
> **GP participant**

including implementing shared decision-making by providing better guidance and support for the clinician and offering more non-pharmacologic alternatives to medicines such as physical/social activities, talking therapies, physiotherapy etc. Global research has identified that non-pharmacological treatment alternatives are underused despite their demonstrated effectiveness in treating several chronic conditions[65]. HSC and the Department of Health[66] have recognised social prescribing and its potential to improve health outcomes. This should be built upon with improved guidance and pathways to alternatives within the health and social care system.

> *"Sometimes the doctor doesn't listen to you when you don't want a tablet and they say oh, well you might need it and they just give it where if you want to give it, I'll take it and get rid of it myself."*
> **Community Participant**

Another method identified in the English review[67] to improve shared decision making was more Structured Medication Reviews (SMR) for those with long-term health conditions. Some community participants said that medication reviews were not readily available, and they needed more confidence to question their healthcare professional. Many needed clarification on the eligibility for reviews and where/who to discuss reviews with, as the information is not readily available. There is a need to support individuals within their community to get the most from their appointments by providing health-literate information and ensuring health and social care staff are open to discussions about a person's medication[50].

Health and social care

Participants were not directly asked about HSC systems. However, discussions naturally emerged relevant to medication safety issues.

> *"I'm not medically trained, and my awareness of what medications are for or dosages etc… it's not up to us to be saying what its [medication] is for and what's not…I feel it's a very precarious area at the minute, especially from my background as a social worker…none of us feel comfortable in doing it, it just leaves room for errors to be made"*
> **Social Worker participant**

Silo working was recognised in this research as having a negative impact on staff's ability to carry out their role regarding medication safety and causing confusion for patients and the public. For example, people discussed having multiple healthcare professionals involved in their care, which meant information could be conflicting, and as a result, they were unsure whose judgement to follow. This "silo mentality" is known to contribute to divisions in healthcare by contributing to communication and workflow issues; patients and the public receiving poorer care[68]; limited understanding of others' roles and responsibilities; and imbalances of authority[69]. Wilson et al. (2016) argue that working together by valuing and having knowledge of other staff and organisations' expertise as a part of common practice can improve medication safety practices[70].

Social workers voiced their concerns that medication safety policies are not always completely clear or implemented consistently. Social workers have unique expertise in medication safety, including their knowledge and awareness of the social determinants of health, engaging and communicating with patients and the public, and helping caregivers support people with their medication use[71]. It is, therefore, important that these policies and procedures on medication are reviewed.

Concerns were raised regarding transitions of care related to confusion around medication changes while in hospital and post-discharge and difficulties accessing medication while transitioning between services. The WHO[72] suggest that to ensure effective medication reconciliation at all points of transition, health and social care staff need adequate training and education, and access to technical resources, including IT support systems with precise and up-to-date records. Concern was also raised for those who have no support at home post-discharge. This highlights the need to consider social factors during transitions of care. This is supported by NICE guidance[73] that advises that transitions of care take account of the person's social and emotional wellbeing and the practicalities of daily living.

Issues with the current system for ordering medication were discussed, including shortages and a need for synchronisation of medicines[i] (being able to order repeat prescriptions at the same time monthly). The synchronisation of medicines, particularly for those who experience polypharmacy, was discussed by health and social care staff as a possible avenue for improving adherence. A study conducted in the US supported this idea, reporting that individuals whose medications were synchronised were around twice as likely to adhere to their medication routine compared to a control group[74]. The current system for ordering medication needs to be explored further to identify potential improvements.

Confusion arising from look-alike/sound-alike medicines was a frequently discussed cause of medication errors. Research by the WHO (2021)[75] found that taking multiple medications with similar shapes, colours, and sizes is one of the most common causes of concern globally. Methods of adherence support, e.g., blister packs, were discussed as potential solutions to these errors, and as the potential to create further confusion due to look-alike/sound-alike medicines. Further investigation is needed to explore how methods of adherence support are currently being used and accessed in NI. The WHO (2021) research also suggests pharmaceutical companies should recognise the potential of errors with look-alike/sound-alike medicines. There is a need for pharmaceutical companies to take the social determinants of health and health literacy into account in the design of medication, it’s packaging and accompanying guidance to counter these issues.

One TMSNI plan aims is to facilitate new ways of connecting staff to share and spread best practice. The plan commits to encouraging networks that enable people to learn and work together to improve medication safety across the health and social care system. The staff in this study welcomed the opportunity to be involved in this research, and their viewpoint, coupled with the community voice, shed light on a prominent research gap in NI. Involving staff developing and implementing of the plan is crucial to enable patients and staff to reflect on the healthcare system together, resulting in meaningful and long-lasting outcomes[76].

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[i] When the refilling of prescriptions allows medications to be dispensed at the same time each month

Know, Check, Ask

The Know, Check, Ask campaign aims to increase public awareness and understanding of the importance of using medication safely. The campaign was welcomed, and participants could see the overall benefits; however, the purposes of the campaign weren't always clear. The 'My Medicines List' also had clear usability issues, including for those with literacy issues, frequently changing prescriptions, and those needing an advocate to complete it; participants suggested digital solutions to these usability issues, such as an app. There were also concerns that the campaign would place the onus solely on the individual to be responsible for their medication. Similar findings were highlighted in a study which evaluated the Know, Check, Ask campaign in Ireland and other studies on patient-held lists[77,78,79].

Health and social care staff also discussed time constraints and staff shortages that could prevent them from routinely practising Know, Check, Ask. These barriers are reported to lead to fewer chances to successfully apply their knowledge and training[80] to involve patients and the public in their medication management[81]. Staff must therefore be part of a functioning culture which that promotes medication safety for all staff from all disciplines, as well as awareness of campaign messages and resources through networks. These barriers must be explored further to successfully embed an organisational culture change around implementing Know, Check, Ask in everyday practice.

> *"If they allocated a member of staff to the table beside this (KCA My Medicines leaflet) for the first while at least to maybe help them do this I think it would take off but unless there's going to be somebody there to help people, not everyone is going to benefit from it"*
>
> **Community Participant**

The research suggests a combined approach to the Know, Check, Ask and other medication campaigns. Providing specific guidance (that can be adapted for particular groups) that could be shared and discussed with their community and/or friends and family, alongside an advertising campaign, would be most beneficial. Alternative methods, including digital technology, should also be explored carefully. At the same time, there would be a need to collect and measure the campaign's impact in terms of sociodemographic information to ensure specific population groups identified at higher risk of medication non-adherence are targeted in the campaigns.

Limitations

Everyone is at risk of medication safety issues; however, this research has found that there are groups of people more at-risk of medication-related harm, including people living in areas of deprivation, older people, people with mental health, addiction, homelessness issues, people with physical and psychological capabilities issues. The current research allowed us to gather an initial understanding of the issues faced by these groups; however, to further improve medication safety in these groups/communities, more effective and meaningful engagement is needed to build an in-depth understanding of how they develop their health knowledge, make health-related decisions, and their understanding and practices about health and medication safety. Gaining this understanding can mean that programmes, messages, or campaigns can be tailored to local needs and take social practices and norms into account.

The research steering group and participants of the Knowledge Exchange Workshop voiced the limitation that lived experiences of people from ethnic minority backgrounds and people who do not have English as a first language were not explored in this research. Previous research has found that language barriers and varied health literacy were key issues in health outcomes for people from ethnic minorities[82] and that those from ethnic minority backgrounds are at an increased risk of medication-related harm compared to the general population[83]. As census figure trends suggest the continual growth of these populations in NI [84], it is important to understand if there are specific issues faced by this at-risk group regarding medication safety.

Policy context

Addressing the social determinants of health and improving health literacy aligns with and enhances the implementation of DoH policies: Delivering Together[85] and Making Life Better[86] and supports public health policy on developing the new Integrated Care System (ICS) for NI. The ICS has a key focus to address the wider determinants of health and wellbeing through a population health approach, addressing the whole life course from prevention and early intervention to treatment and end-of-life care[87]. In addition, it has included health literacy within the values and principles.

Conclusion

This exploratory research is the first of its kind in NI; it successfully collected people's lived experiences of medication use and raised awareness of the social determinants of health and medication safety. A CBPR approach ensured that people in communities and other key health and social care, government and academia stakeholders were actively engaged in this research. Through this approach, the stakeholders were integral in co-constructing the research process. Their valuable insights and knowledge influenced the research development, design, sample, research questions, analysis, reporting and recommendations. This collaborative approach shaped the research, ensuring people in communities were at the centre of the work, but also enhanced the stakeholder's and research participants' knowledge and understanding of medication safety and the social determinants of health.

The research identifies that medication safety is a health inequalities issue and that social factors impact people's ability to take their medication safely. In line with the WHO Global Commission on the Social Determinants of Health,[9], this research expanded the knowledge base on the social determinants of health and supports the need to develop the workforce and raise awareness and understanding in the community. Further actions to improve medication safety need to consider how people's daily living conditions and power, money and resources will impact their ability to engage with health and social care services and actively manage their medication.

Key learning

- Medication safety is a health inequalities issue which is often overlooked in research, policy, and practice.
- Every person's life is unique, shaped by different experiences and the social determinants of health. Recognising these differences is essential for preventing medication-related harm and improving health outcomes for all.
- People have varying abilities accessing, understanding, appraising, remembering, and using information about their medication, and this can sometimes go unnoticed by health and social care staff. Health literacy around medication needs to improve to reduce medication-related harm.
- To encourage reporting of medication errors, people need to know the processes along with the importance of reporting and be able to have open and honest conversations with health and social care staff without fear of repercussions.
- People want to be more involved in decisions about their medication and welcome non-pharmacological alternatives.
- There are ongoing issues within the health and social care system that may prevent people from taking their medication safely and it appears the system does not routinely account for people’s social circumstances and health literacy.
- The Know Check, Ask campaign was welcomed, however more guidance and support are needed for people in the community and health and social care for it to be embedded in everyday practise.
- Local needs, social practices and norms need to be considered in the implementation of the TMSNI plan and all other medication safety work in Northern Ireland.

6. Recommendations

Following the analysis, all those who were involved in any aspect of the research process were invited to a Knowledge Exchange Workshop (KEW). During the workshop, participants discussed the focus group findings and suggested recommendations and practical applications for the future. The following recommendations, which are separated into two sections, are based on the insights gained from the research and input received during the KEW. This chapter is sectioned as follows:

A) Recommendations to inform the implementation of the TMSNI plan, and
B) Recommendations beyond the TMSNI plan.

A) Recommendations to inform the implementation of the TMSNI plan

A1 Take into account the social determinants of health and health literacy in the future implementation of all TMSNI action plans.

The following actions are necessary to support this recommendation:

A1.1 New and existing adherence services need to incorporate the social determinants of health and health literacy

A1.2 Use the learning from this research and other adherence and polypharmacy examples of best practise (e.g., Medicines Optimisation of Older People (MOOP), iSympathy) to develop, test and implement models of care that support patients to take their medicines as recommended.

A2 Co-produce, deliver and evaluate a cascading community health literacy programme focused on medication safety.

The following actions are necessary to support this recommendation:

A2.1 The programme content needs to include:

- ***Medication safety:*** The importance of medication safety, how harm can arise with medicines, introduction and awareness of the Know, Check, Ask (KCA) campaign and the ‘My Medicines List’
- ***The reasons why, the name, shape, colour of a prescription might change*:** branded versus generic names, how supply might affect your prescription and being aware of look alike, sound alike medicines.
- ***Finding credible information about your medication:*** sources of reliable information about your medication and identifying misinformation
- ***Getting the most out of your appointment with your health professional:*** Exploring your options and choices; useful tips and reminders; knowing the purpose of/how to prepare for medicine reviews, and an introduction to shared decision making including the '5 Moments of Medication Safety'
- ***The importance of reporting errors:*** who to report to, the processes and outcomes of reporting, the community pharmacy and RAPID safe disposal outlets, and to MHRA and pharmaceutical companies through the yellow card scheme.
- ***Navigating the health and social care system:*** Community pharmacy offering the Pharmacy First scheme, the prescription process, other HSC services and how services are changing – Multi Disciplinary Teams (MDT), Integrated Care System (ICS), social prescribing, accessing/eligibility for blister packs including their benefits and drawbacks

A2.2	Use the developed content in all relevant training, education and awareness raising programmes that target specific population groups based on their needs and experience. The core messages must remain the same to ensure there is consistency across NI and the life course. Examples where the training content could be used include, Building the Community Pharmacy Programme (BCPP), The Pharmacy Schools programme and its potential expansion to secondary schools.
A3	**Develop a communication, awareness, promotion and engagement strategy for the TMSNI plan for patients and the public and health and social care staff** *The following actions are necessary to support this recommendation:* ***Actions for TMSNI work***
A3.1	Co-design key communication messages into a strategy for the TMSNI plan. ▪ The strategy needs to specify when and how the messages will be promoted to patients and the public, as well as how they will be integrated into health and social care internal communications (e.g., intranets, emails) ▪ The messages must be tailored to reach different audiences e.g., different people in the community and different health and social care staff roles.
A3.2	Develop and publicise (or endorse one that already exists) an up-to-date information resource where people can find information on what a medicine review is, eligibility for medicine reviews, who in HSC provides reviews and how people can access them.
A3.3	Develop a campaign to raise awareness of the benefits of reporting medication issues, where and how to report e.g., community pharmacy, yellow card scheme
A3.4	Develop a campaign to raise awareness of how to safely dispose of unused/unwanted medicines e.g., pharmacy, RAPID bins
A3.5	Develop and implement an evaluation framework for KCA and any other medication safety messages/ campaigns/information to measure the impact and reach. It is essential that the following data is collected: ▪ baseline socio demographic information (to show if the impact is different in areas of deprivation and with groups who are at higher risk of medication related harm) ▪ reach and use of the campaign's tools by different health and social care roles (to show impact across HSC) ***Actions specific to the Know, Check, Ask (KCA) campaign***
A3.6	Co-design health literate guidance for the KCA campaign with tips and techniques to discuss the content and messages of the campaign with people in the community and/or friends and family. The guidance must be developed and adapted to reach different audiences e.g., people in the community and different health and social care staff roles
A3.7	Co-design a comprehensive KCA advertising campaign, for maximum impact this needs to be delivered alongside the community health literacy programme (recommendation 2)
A3.8	Explore the development and endorsement of digital versions of the KCA 'My Medicines' leaflet e.g., phone app.
A4	**Review and revise all current undergraduate, postgraduate and Continuing Professional Development (CPD) training and learning on medication safety for all those who work in health and social care to ensure social determinants of health and health literacy are included.** *The following actions are necessary to support this recommendation:*

A4.1 It is imperative that training and learning programme content for HSC staff be made mandatory, covering the following topics:

- ***Social determinants of health and health inequalities:*** their impact upon medication safety and what extra support is needed for people to reduce medication harm and increase adherence.
- ***Health literacy:*** Understanding health literacy, role of health and social care in improving health literacy and how health literacy can impact medication safety
- ***Medication safety campaigns/tools:*** Implementing and using the Know, Check, Ask and 5 Moments of Medication Safety tools.
- ***The literature base:*** The learning and lived experiences from this research, the iSympathy project and other relevant studies.
- ***PPI:*** Medication safety is everyone’s responsibility, the case for change in the TMSNI plan, the importance of patient and public involvement and what that means in their role
- ***Shared decision making:*** Skills to engage in Shared Decision Making with patients about medication, including listening, being non-judgemental and empathetic, taking a joint approach when making decisions, how to support patients to take medication safely, taking the social determinants of health into account in medication reviews.
- ***Communication:*** How to sensitively address patients’ misconceptions and questions about medication, including incentives and cost and queries about 'Big Pharma', and where to signpost patients to find reputable information to make informed decisions e.g., different brands of the same medication, explaining the benefits and purpose of preventative medicines to patients, the purpose and benefits of medication reviews to patients
- ***Reporting:*** How to overcome patient barriers to reporting medication issues and concerns to encourage and support reporting.

A4.2 Develop easily accessible resources for staff to use when implementing the learning from training e.g. pictograms and/or links to reputable informative websites that they can share with patients.

A5 Inform, encourage, and support HSC staff to participate in, develop, test and implement solutions around medication safety, social determinants of health and health literacy.

The following actions are necessary to support this recommendation:

A5.1 Encourage staff to take part in developing solutions e.g., taking part in research on medication safety and lived experience research.

A5.2 Develop a Project Echo network for medication safety open to all who support people with medication safety (including health and social care and community and voluntary sector staff)

A6 Explore further with HSC staff the enablers and barriers to implementing KCA in their everyday practise (e.g., time, support, skills) and use the findings to develop realistic guidance to embed organisational culture change around practising KCA

A7 Explore with health and social care staff, their needs and requirements in relation to their role and responsibilities in the implementation of the TMSNI, including a review of current policies and procedures. This work needs to be prioritised with social workers and others who work with people in their own homes.

A8 Use the learning from the development of the new Integrated Care System (ICS) and explore with health and social care staff how they can better work across disciplines and share patient information to improve medication safety

A9 Ensure transitions of care takes account of the person's social and emotional wellbeing, as well as the practicalities of daily living as stated in NICE guidance.

A10 The lived experiences of patients need to be brought into discussions with pharmaceutical companies so that the social determinants of health and health literacy are considered in the design of medication, it's packaging and accompanying information/guidance.

A11 Explore the current system for ordering medication

The following actions are necessary to support this recommendation:

A11.1 Develop a working group (including patients and the public and HSC staff) to explore potential improvements to:

- Producing a clear description of the current system
- Ways to improve the ordering of repeat prescriptions
- Better synchronisation of prescriptions (e.g., to once a month)

A11.2 Explore with health and social care staff how they can work collaboratively and communicate more effectively to identify and manage medicine supply chain issues and shortages and implement the learning.

A12 Ongoing digital developments within HSC need to take into account medication safety, the social determinants of health and health literacy

The following actions are necessary to support this recommendation:

A12.1 All digital systems that hold patient information need to have a function to record social factors that may be impacting on patients’ health or their ability to take medication as prescribed

A12.2 All digital systems that hold patient information need to allow patients to access a list of their medications and their purposes (print out or online) to improve their health literacy and to help them complete the KCA 'My Medicines' leaflet

A12.3 All digital systems that hold patient information need to take learning from recommendation 11 on ordering prescriptions and synchronising medication and include in their development.

A13 Maintain the ongoing partnership with the community and voluntary sector and patient and public involvement (PPI) in all workstreams of the medication safety plan, including a review of the function and membership of the TMSNI working groups and inviting community and voluntary sector representatives and patients and the public to join.

A14 Conduct further research to gather a more in-depth understanding of the social factors that impact on medication safety in Northern Ireland

The following actions are necessary to support this recommendation:

A14.1 Further investigate population groups who have specific medication safety and adherence issues identified through this research including:

- those who have experienced poor mental health, addictions or homelessness
- those who have limited physical capabilities such as difficulty swallowing, hearing impairments, and general mobility issues
- those who have psychological capability issues such as those with learning difficulties/disabilities/impairments, those with dementia
- those with caring responsibilities
- Children under 18 (and parents)
- Those living in areas of social deprivation and/or isolation

A14.2 Prioritise investigating at-risk groups identified who were not included in this study including ethnic minority groups and those with English not as a first language.

B) Recommendations beyond the TMSNI plan

B1 DoH to explore how the HSC shared decision-making guidance and resources have been implemented and how they could be used to improve patient involvement and shared decision making about health and medication use.

B2 DoH to consider how pathways for non-pharmacological alternatives to medication can be created and sustained.

The following action is necessary to support this recommendation:

B2.1 Work with the NI Regional Social Prescribing Development Board and General Practices to create pathways for social prescribing and other community support so that alternatives to medication are offered and accessible to patients.

B3 DoH to review the arrangements that are in place for people who experience difficulty in attending health and social care appointments and medicine reviews due to social factors e.g., an independent support person, transport and implement the learning.

B4 DoH to continue to explore how methods of adherence support are currently being used including how they are accessed (e.g., blister packs) and implement the learning.

B5 The new Integrated Care System (ICS) NI Outcomes Framework needs to explore appropriate high-level indicators to measure medication prescribing rates and medication safety, linked to social deprivation for population health planning.

B6 Reconvene the HSC Regional Health Literacy forum to help co-ordinate health literacy work in NI.

B7 CDHN and TMSNI programme board disseminate the research findings to generate discussions for the way forward and add to the literature base.

The following actions are necessary to support this recommendation:

B7.1 CDHN must disseminate the findings to all those who took part in any aspect of the research.
B7.2 Consider the options for writing and publishing findings in relevant academic journals.
B7.3 Present the findings at relevant NI, UK, ROI and international events and conferences.
B7.4 CDHN to produce a report describing the benefits of the CBPR approach in engaging with people in the community and health and social care in gathering lived experiences.

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