



# Our Lives, Our Meds, Our Health

Exploring medication safety through a social lens

Helen McNamee, Caoimhe Shields, Joanne Vance

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# Introduction

This is an Executive Summary of the 'Our Lives, Our Meds, Our Health: Exploring Medication Safety through a Social Lens' report by Community Development and Health Network (CDHN). The research addresses a gap in the evidence base on how Social Determinants of Health (SDOH) impact medication safety in Northern Ireland (NI). The Department of Health (DoH) Strategic Planning and Performance Group (SPPG) commissioned the research as part of the Transforming Medication Safety in Northern Ireland (TMSNI) plan<sup>1</sup>. The research aim was to

Discover the social circumstances behind unsafe medication practices and avoidable medicationrelated harm to inform the implementation of the Transforming Medication Safety in NI plan using a community-based participatory research (CBPR) approach.

The TSMNI plan was developed in response to the World Health Organisation's (WHO) Third Global Patient Safety Challenge 'Medication without Harm'<sup>2</sup>. Know, Check, Ask (KCA) is a WHO medication safety campaign, adapted by DoH as part of the plan<sup>1</sup>. One of the research objectives was a critical reflection of the KCA campaign.

CDHN is NI's leading organisation working to empower communities, improve health and well-being and reduce health inequalities. We recognise, value, and gather evidence to understand the SDOH and reflect peoples' lived experiences.

# Background

Research on health inequalities shows that health and illness follow a social gradient - the lower a person's socioeconomic position, the poorer their health is likely to be. This downward slope is the product of the social determinants of health (SDOH)<sup>3</sup>. The SDOH have a larger impact on health outcomes than genetic makeup or lifestyle behaviours and individuals' ability to change is constrained by social circumstances<sup>4</sup>. 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 areas<sup>5</sup>. In addition, 50% more prescription items are dispensed in the most deprived areas of NI compared to the least deprived<sup>6</sup>.

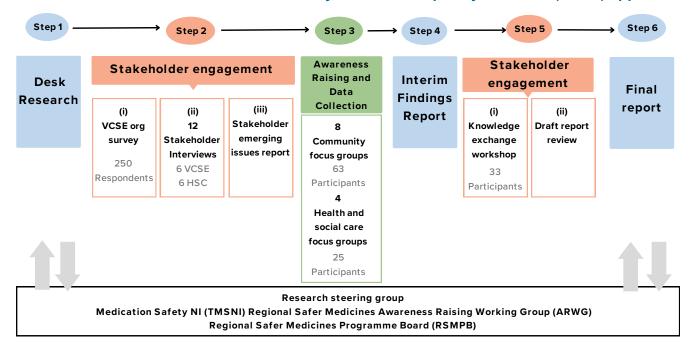
There is a dearth of studies on the SDOH and its relationship to medication safety and no studies of this nature could be found relating to the NI population. A recent systematic review found a significant relationship between the SDOH and medicine adherence and concluded that the relationship warrants more attention from healthcare providers and policymakers<sup>7</sup>. Research has also shown that limited health literacy is associated with patients having less recall and adherence to medical instructions and self-care regimes; and more negative beliefs about medication, such as fear of medicines<sup>8</sup>.

International research 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<sup>9</sup>. Although the benefits of shared decision-making are increasingly recognised it is not yet routinely practised in every setting<sup>10</sup>. There is no known qualitative research on reporting medication errors and concerns or making decisions about medication in NI from the perspective of patients and the public.

i. 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

# Methodology

This exploratory qualitative research study used a community-based participatory research (CBPR) approach. It is an approach whereby researchers and stakeholders form equitable partnerships and coconstruct research for the mutual and complementary goals of community health improvement and knowledge production<sup>11</sup>. The approach had interconnected stages (see figure below) to engage key stakeholders (people in the community; Voluntary Community & Social Enterprise (VCSE) organisations; Health and Social Care (HSC) staff; and those working in Government and academia). They played a fundamental role in co-constructing the research process and shaped the research development, design, sample, research questions, analysis, reporting and recommendations.



#### Our Lives, Our Meds, Our Health Community Based Participatory Research (CBPR) approach

### Step 1: Desk research:

The literature review gathered existing evidence on SDOH and medication-related harm.

### Step 2: Stakeholder Engagement:

- i. VCSE organisation online survey: The purpose was to explore the VCSE sector's awareness and knowledge of medication safety-related issues in their communities. Participants could also register their interest to be involved in other stages (250 responses).
- ii. Stakeholder Interviews: The purpose was to further scope out the topic and research methodology.12 were conducted: 1 community, 5 VCSE & 6 HSC (2 also worked in academia).
- **iii. Stakeholder Emerging Issues Report:** This is the survey and interview findings. It helped develop the research process, including the focus group sample and topic guides.

#### Step 3: Awareness raising and data collection - Focus groups:

Three target groups were identified for the sample. 1) People from socially disadvantaged communities; 2) those at risk of medication harm; and 3) people who work in HSC. The focus groups began with an awareness-raising session that included introducing the KCA campaign.

#### Step 4: Interim Report:

Focus group transcripts were analysed using thematic analysis and the findings were presented in an interim report which was shared with the research steering group and TMSNI team.

#### Step 5: Stakeholder Engagement

- i. Knowledge Exchange Workshop (KEW): This 2.5-hour workshop brought together research participants, people from the community, VCSE sector staff, HSC staff and DoH staff (33 participants) to read and interpret the interim findings and shape the recommendations.
- **ii. Draft report review:** This draft report was shared with the KEW participants, research steering group and research participants for review and feedback before the final report publication.

Step 6: Final Report A full version of the report can be found at www.cdhn.org

### **Ethical considerations**

Capacity & Capability approval was granted in the Northern HSCT, Southern HSCT, South Eastern HSCT, and Western HSCT<sup>ii</sup>. In addition, the Social Research Association (SRA) Research Ethics Guidance<sup>iii</sup> was followed throughout the study.

# Key findings: Community and HSC staff focus groups

In total, 88 people participated in the focus groups; 63 community participants across 8 focus groups and 25 people working in HSC across 4 focus groups. Thematic analysis established six key themes which are presented below.

### Theme 1: Social Determinants of Health (SDOH)

People both intentionally (making an active decision) and unintentionally (by forgetting or circumstances out of their control) did not take their medication as prescribed. There were many social factors found to contribute to this:

- Busy lives being out of routine/socialising/unusual working patterns.
- Caring for and **prioritising others' needs**.
- Living alone and having limited social support.
- Social stigma attached to some medication.
- Rural/physical isolation.
- Access to transport.
- Varied **physical capabilities** including difficulty opening medication, measuring doses, and swallowing tablets.
- Varied psychological capabilities including difficulty managing and remembering medication.
- Poor mental health, addiction, and trauma the addictive nature of prescription medication was not always considered by HSC staff.
- Difficulty accessing medical appointments and limited time during appointments.
- Difficulty ordering prescriptions.
- HSC staff were aware of social factors that impact medication safety, however, community participants voiced that these were not always considered in their care.

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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. (Community participant)

ii. 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.

iii. Social Research Association (2021) Research Ethics Guidance

### **Theme 2: Health Literacy**

Community participants shared their experiences of accessing, receiving, and understanding instructions, advice, and guidance with their medication. This was **influenced by many different sources** including friends and family, community networks, their research, and the wider media. Experiences included:

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)

- Not being aware of the importance of taking medication safely and the advice, guidance and support that healthcare professionals can provide.
- Being unsure of their medication's name and purpose and the process to get a prescription.
- Not understanding the benefit of preventative medication and why a certain medication has been prescribed and concerns around 'Big Pharma'.

HSC staff weren't always aware of people's **health literacy needs**. Community participants

voiced that they would like **more support** from HSC staff with their medication and more information and guidance about medications including clearer instructions e.g., dosage and timings.

### Theme 3: Reporting issues and concerns about medication

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

- **Enablers** to reporting included: good relationships and trust with healthcare professionals; healthcare professionals starting the conversation; being approachable, personable, open and non-judgemental and recognising each individual's circumstances.
- Barriers to reporting included:
  - Not realising they are taking their medication incorrectly.
  - Not knowing the importance of reporting errors or how to report, whom 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 HSC staff that an error was made.
  - Wanting to please healthcare professionals, getting a GP appointment to discuss concerns, and not wanting to bother the GP.
  - A fear of repercussions e.g., social services involvement.
  - Being unaware of how to dispose of unused medications, e.g., in a pharmacy, to have an avenue to discuss why the medication was not being taken.

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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)

### Theme 4: Being involved in decisions about medication

It was clear that people can see the benefits of being involved in decisions about their medication, and most would like to be given the opportunity to be more involved.

- **Positive** experiences included: working with healthcare professionals to change medication, medication being fully explained and being given the opportunity to make decisions.
- **Negative** experiences included: feeling their opinions were not listened to; medication being prescribed that would not address their issue; being told they must take medication.
- **Barriers** included: lacking the confidence to question a doctor; fear of authority and what would happen as a result; lack of GP appointments and short appointment times.
- **Enablers** included, HSC staff directly asking people their views; staff who are approachable, understanding, and non-critical; staff helping people learn more about their medication; and staff using a personalised approach to find out what matters to the patient.
- Some people said they had **never had a medicine review**. They were welcomed by participants to reduce or change the medication they were taking.
- In some situations, people felt an alternative to medication may be more appropriate and were open to **non-pharmacological alternatives** including social prescribing and community programmes.

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)

### Theme 5: Health and Social Care

Participants were not directly asked about HSC systems; however, discussions naturally arose on the topic.

- HSC staff were aware of the differences in their knowledge regarding medication practices and the benefit of learning from each other.
- **Silo working** in HSC 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 HSC Trust (HSCT) area boundaries e.g., the administration of blister packs.
- 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 (refills once a month).
- 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)

I'm not medically trained, and my

awareness of what medications are for

or dosages etc...it's not up to us to be

- Medication can change during **transitions of care**, and this can be confusing for patients and some transitions of care may not be meeting the needs of specific target groups.
- HSC staff value having their voice heard, sharing their experiences, and learning from others.

### Theme 6: Know, Check, Ask (KCA)

Participants were asked for their initial thoughts on the KCA campaign and its resources. Knowledge of the campaign and experience of using its resources were varied as it was a relatively new campaign launched at the same time the focus groups were 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 KCA would **fall solely on the individual.**
- Some people **need help** to understand their medication and complete the leaflet.

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- 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 KCA with patients and the public.

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)



Knowledge Exchange Workshop (KEW) participants reviewing the findings and shaping the recommendations 27 October 2022

# Discussion

### **SDOH and Health Literacy**

The findings show that people's everyday lives and social circumstances can impact their ability to take medication as prescribed, supporting other research<sup>7</sup> that this warrants more attention in healthcare. Health literacy was a dominant theme, with participants having varying abilities in accessing, understanding, appraising, remembering, and using information about their medication. This was influenced by many different sources including friends, family, community networks and wider media. A recent WHO<sup>12</sup> report notes that information and resources need to be designed to accommodate different abilities and cultural backgrounds, and to be discussed among family and friends rather than individuals. To ensure reliable and trustworthy information on medication safety is shared throughout the community, a community health literacy programme should be developed and adapted to local needs and stages in life course while considering social practices and norms. These findings also highlight the need for staff training on health literacy and communication, the SDOH and health inequalities.

#### **Reporting medication issues and concerns**

There were positive and negative experiences of reporting errors and concerns about medication, consistent with other research<sup>13</sup>. Addressing barriers to reporting can improve peoples' medication safety practices and enable HSC staff to learn from mistakes and implement preventative measures for the future<sup>14</sup>. Improving health literacy, and person-centred care can also play a key role in enabling the reporting of medication issues.

### Making decisions about medication

Participants expressed a general openness to being more involved in decisions about their medication. Issues of overprescribing due to a lack of shared decision-making were raised. Participants highlighted situations where they felt a non-pharmacological alternative may have been more appropriate, supported by identified benefits of non-pharmacological alternatives<sup>15</sup>. Some community participants had difficulty accessing medication reviews and information about eligibility and processes for reviews was not always available. Others lacked the confidence to question their healthcare professional. Providing health literate information about reviews and ensuring HSC staff are open to discussions about medication is crucial to improving shared decision-making around medication<sup>10</sup>.

### Health and social care

Silo working was recognised as impacting medication safety due to patients receiving conflicting information from staff, known to be a contributor to divisions in healthcare<sup>16,17</sup>. Social workers, who have unique expertise regarding medication safety<sup>18</sup> but are not medically trained, voiced their concerns that medication safety policies are not always clear or implemented consistently. It is therefore important that the policies and procedures are reviewed. Concerns were raised regarding medication between transitions of care and for those who have no support at home. This highlights the need to consider social factors during transitions of care which are supported by NICE guidance<sup>19</sup>. Issues with the current system for ordering medication included shortages and a lack of synchronisation of medicines<sup>iv</sup>. Synchronisation was suggested by HSC staff as a way of improving adherence and is supported by research elsewhere<sup>20</sup>. The current system for ordering medication needs to be explored further. Confusion arising from look-alike/sound-alike medicines was a frequently discussed cause of medication errors, echoed by WHO<sup>21</sup>. Methods of adherence support, e.g., blister packs, were discussed as being potential solutions, but their limitations were also recognised. Further investigation is needed to explore methods of adherence support in NI. There is also a need for pharmaceutical companies to take the SDOH and health literacy into account in the design of medication, packaging, and guidance.

iv. When the refilling of prescriptions allows medications to be dispensed at the same time each month

### Know, Check, Ask (KCA)

The KCA campaign was welcomed, and the overall benefits could be seen by participants; however, the purpose of the campaign was not always clear. There were concerns that the campaign would place the onus solely on the individual to be responsible for their medication. Similar findings were highlighted in other studies<sup>22,23</sup>. More guidance is needed for people to share and discuss the campaign with their community and/or friends and family and digital solutions should be explored. HSC staff discussed time constraints which can prevent them from routinely practising KCA. To embed an organisational culture around KCA, the enablers and barriers to its use must be explored further.

### Limitations

Everyone is at risk of harm from medicines; however, this research has found that there are groups of people more at-risk. These findings have gathered an initial understanding of the issues, however, to further improve medication safety, more effective and meaningful engagement is needed so that programmes, care, and campaigns can be tailored to local needs and take social practices and norms into account.

### Conclusion

This exploratory research is the first of its kind in NI which successfully collected people's lived experiences of medication use and raised awareness of the SDOH and medication safety. A CBPR approach was used to ensure that key stakeholders played an integral role in co-constructing the research process. This collaborative approach also enhanced the stakeholders' and research participants' knowledge and understanding of the topic. The research identifies that medication safety is a health inequalities issue and that social factors impact people's ability to take their medication safely. 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 take an active role in managing 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 in accessing, understanding, appraising, remembering, and using information about their medication, and this can sometimes go unnoticed by HSC 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 HSC staff without fear of repercussions.
- People want to be more involved in decisions about their medication and welcome nonpharmacological alternatives.
- There are ongoing issues within the HSC 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 KCA campaign was welcomed, however, more guidance and support are needed for people in the community and HSC for it to be embedded in everyday practice.
- 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.

# **Recommendations**

The following recommendations are split into two sections, A) Recommendations to inform the implementation of the TMSNI plan, and B) Recommendations beyond the TMSNI plan. Some of the recommendations have specific action points that can be seen in the full report (found at cdhh.org).

#### A) Recommendations to inform the implementation of the TMSNI plan

- 1. Take into account the SDOH and health literacy in the future implementation of all TMSNI action plans.
- 2. Co-produce, deliver and evaluate a cascading community health literacy programme focused on medication safety.
- 3. Develop a communication, awareness, promotion and engagement strategy for the TMSNI plan for patients and the public and HSC staff.
- 4. Review and revise all current undergraduate, postgraduate and Continuing Professional Development (CPD) training and learning on medication safety for all those who work in HSC to ensure the SDOH and health literacy are included.
- 5. Inform, encourage, and support HSC staff to participate in, develop, test and implement solutions around medication safety, SDOH and health literacy.
- 6. Explore further with HSC staff the enablers and barriers to implementing KCA in their everyday practice (e.g., time, support, skills) and use the findings to develop realistic guidance to embed organisational culture change around practising KCA.
- Explore with HSC 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.
- 8. Use the learning from the development of the new Integrated Care System (ICS) and explore with HSC staff how they can better work across disciplines and share patient information to improve medication safety.
- 9. Ensure transitions of care takes account of the person's social and emotional well-being, as well as the practicalities of daily living as stated in NICE guidance.
- 10. The lived experiences of patients need to be brought into discussions with pharmaceutical companies so that the SDOH and health literacy are considered in the design of medication, its packaging and accompanying information/guidance.
- 11. Explore the current system for ordering medication.
- 12. Ongoing digital developments within HSC need to take into account medication safety, the SDOH and health literacy.
- 13. 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.
- 14. Conduct further research to gather a more in-depth understanding of the social factors that impact medication safety in Northern Ireland.

#### B) Recommendations beyond the TMSNI plan

- 1. 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.
- 2. DoH to consider how pathways for non-pharmacological alternatives to medication can be created and sustained.
- 3. DoH to review the arrangements that are in place for people who experience difficulty in attending HSC appointments and medicine reviews due to social factors e.g., an independent support person, transport.
- 4. 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.
- 5. 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.
- 6. Reconvene the HSC Regional Health Literacy forum to help coordinate health literacy work in NI.
- 7. CDHN and TMSNI programme board disseminate the research findings to generate discussions for the way forward and add to the literature base.

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For further information please contact Helen McNamee Research and Policy Manager E: helenmcnamee@cdhn.org

# Community Development and Health Network (CDHN)

30A Mill Street Newry Northern Ireland BT34 1EY E: info@cdhn.org T: +44 (0) 28 3026 4606



