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LET'S TALK DIFFERENTLY ABOUT MEDICINES

Empowering patients and public to address polypharmacy amongst older people







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Executive Summary

Let's Talk Differently About Medicines (LTDAM) is a story-based intervention designed to spark more meaningful conversations about polypharmacy among older adults. Developed by academic researchers and rooted in lived experience, the stories reflect the emotional, practical, and relational dimensions of managing multiple medicines. This project, delivered and evaluated by Care City Innovation CIC, set out to operationalise the stories, test their impact, and develop a facilitator guide to support independent delivery.

This project was funded by a Queen Mary University of London (QMUL) Impact Accelerator Award, and delivered in collaboration with the QMUL team of researchers Professor Deborah Swinglehurst, Dr Nina Fudge and Dr Alison Thomson, who developed the LTDAM intervention.

Background and Rationale

Polypharmacy, the use of multiple medications, affects one in five adults in the UK and is especially common among older people. Although Structured Medication Reviews (SMRs) have been introduced to address this, evidence shows they often fall short due to time pressures and lack of patient-centred dialogue. LTDAM addresses these gaps by offering a different kind of resource: character-driven stories designed to provoke reflection, shift perspectives, and empower patients to engage in conversations about their medicines.

Project Delivery and Evaluation

Care City ran 14 storytelling sessions with 126 residents (82 of whom met the target criteria of being 65+ and on 5+ medications) across North East London. Sessions were delivered in familiar, community-based settings and shaped through co-design with local people. The facilitator guide was iteratively developed and refined through this process, informed by participant feedback and facilitator experience.

Evaluation used group and 1:1 follow-ups with 60% of cohort participants to explore changes in attitudes, behaviours, and confidence around talking about medicines. Visual and narrative methods were used to surface reflections, and thematic analysis of follow-up data revealed clear evidence of impact.

Key Findings

- **In the room**: The stories prompted honest, emotionally resonant conversations. Participants related strongly to the characters and shared their own challenges, fears, and frustrations about medication.
- Beyond the room: Many participants reported changes in how they think about and manage medicines, including:
 - Initiating conversations with GPs or pharmacists.
 - Reducing or reviewing medication in consultation with healthcare professionals.



- o Talking to family, friends, and community members about medication concerns.
- Running or planning to run their own sessions.

Recommendations for scaling

To scale the impact of LTDAM, following steps are recommended:

- 1. **Maintain free, open access** to the stories and facilitator guide via the project website.
- 2. **Support grassroots delivery** by volunteers, community groups, and retired professionals.
- 3. **Establish a dedicated hosting organisation** (e.g. a Community Interest Company) to steward the resource and promote quality.
- 4. **Develop a dedicated mobile app** to increase accessibility and include an Al-powered chatbot to support facilitation.
- 5. **Launch a strategic media campaign** to raise awareness and normalise medication conversations.
- 6. **Explore integration** with NHS pathways (e.g. social prescribing, PCNs).
- 7. **Create accredited training pathways** to build credibility in clinical and community settings.

Conclusion

LTDAM demonstrates that storytelling can unlock conversations about medicines that standard clinical tools cannot. Participants left sessions more reflective and confident — and many took steps to challenge or change their medicine use. With the right infrastructure, coordination, and digital support, LTDAM is well-positioned for national rollout, offering a human-centred, scalable solution to one of the most pressing challenges in modern healthcare.

Introduction

"Improving quality of life in older age sometimes means less medicine, not more. It is essential that all patients, but especially those in later age, are able to have realistic discussions with their doctors."

Chief Medical Officer Annual Report, November 2023.

Polypharmacy and Older Adults

Polypharmacy — the use of multiple medicines — is an escalating concern both in the UK and globally, currently affecting around 20% of adults. National policy has recognised the significance of this issue. The 2021 National Overprescribing Review and the subsequent AHSN National Polypharmacy Programme (2022) have prioritised action on polypharmacy, particularly through the implementation of Structured Medication Reviews (SMRs). These reviews target people taking 10 or more medicines — often older adults who are at greater risk of harm due to side effects, interactions, and medication-related complications.

Polypharmacy can also affect quality of life and increase healthcare waste. Medicines make up approximately 20% of the NHS's carbon footprint, and between 30–50% of medicines prescribed for long-term conditions are not taken as intended. Addressing unnecessary or unwanted medicine use is not only a safety issue, but also a sustainability issue .

Despite being a key opportunity to address these challenges, medication reviews are often underutilised or ineffectively implemented. Evidence and patient experience suggest that these reviews are frequently time-pressured, lack clarity of purpose, and have limited impact on treatment plans. Many patients report difficulty voicing concerns, assuming that taking multiple medicines is simply unavoidable. Too often, the burden of managing polypharmacy remains invisible to professionals. To truly support people, we need more space for real conversations that acknowledge this burden — and more support to reduce it where appropriate.

Let's Talk Differently About Medicines

Let's Talk Differently About Medicines (LTDAM) is one response to this challenge. Developed by academic researchers at QMUL, LTDAM is based on insights from the APOLLO-MM study — an in-depth ethnographic investigation into how people live with and manage multiple medicines. The research, conducted by Professor Deborah Swinglehurst and Dr Nina Fudge, involved over 400 hours of observation across general practice, community pharmacy, and patients' homes, alongside narrative interviews and filmed medication reviews. The findings highlighted systemic issues: reviews that are unclear, rushed, and disconnected from patients' lived experiences[1,2]. The researchers then worked closely with Dr Alison Thomson (QMUL) and



members of PenPEG (Peninsula Public Engagement Group) to build the LTDAM stories through a design-led process [3]. This involved iterative workshops, and visual and narrative prototyping to translate the complex research insights into compelling, human-centred stories that could stimulate new ways of thinking and talking about medicines. While SMRs are endorsed by NICE and intended to enable shared decision-making, the current evidence on their impact is limited[4,5]. Reviews often fail to achieve meaningful engagement or lead to substantive changes in care, in part because they don't sufficiently consider what matters most to the individual[6,7,8].

LTDAM was designed to support better conversations — not by providing more information, but by introducing a different kind of resource. At the heart of the approach are stories: personal, character-driven narratives co-designed with patients to reflect the emotional, relational, and practical dimensions of living with multiple medicines. Storytelling is a well-established health communication tool. It's engaging, inclusive, and capable of opening up new ways of thinking. Unlike technical leaflets or formal guidelines, stories invite reflection. They help people explore difficult questions, consider different perspectives, and connect with others.

Rather than aiming to inform in a traditional sense, LTDAM is intended as a catalyst — helping people reflect on their own experiences, and enabling more meaningful dialogue with clinicians, carers, and peers. The stories highlight issues such as medication burden, power dynamics in healthcare, and the emotional labour of long-term treatment — topics that are rarely addressed head-on in medication reviews.

The LTDAM stories

LTDAM consists of seven stories which are available both <u>online</u> (in text and audio formats) and in print. These are stories to inspire new avenues for discussion between clinicians and patients about their medicines and care. Each story is also accompanied by questions to generate discussion. Below is a summary of each story with an example question.



- **1 Life is meant for Laughing** Marge is a socially active, fun-loving woman who lives independently in a council flat with her dog. She feels a bit fed up having to take pills, especially as she keeps being prescribed new ones. She follows her own rules on how to take them. These self-imposed rules are different to the advice her doctor gave her. Sorting out her pills takes up a lot of time and energy. When a new doctor joins her practice Marge considers discussing her long-standing concerns about her medicines.
 - Are you concerned, like Marge, that you may be on too many medicines? What are your concerns?
- **2 What Is It All For?** Danny, a once-strong former boxer and docker, now struggles with fatigue and declining health after a stroke, spending much of his time managing a growing list of medications for himself and his wife. Staying organised and in control of their prescriptions is very demanding, involving almost daily visits to the pharmacy or GP. He feels frustrated and doubtful about the purpose and effectiveness of the treatments.
 - What expectations do you have for your medicines and how confident are you that they are working for you?
- **3 'Keeping Going': Are My Medicines A Help or a Hindrance?** Lorna is an 84-year-old woman adjusting to life in a warden-controlled flat. She struggles with her mobility and the challenges of managing a complex medication routine. She feels overwhelmed by the number of pills she takes and frustrated by the difficulty of staying on top of her prescriptions. A conversation with her friend and a newspaper article about the potential harms of taking lots of medicines gives her courage to ask her new doctor about reducing her medicines. Until then she had been reluctant to ask her doctor about this issue as she was afraid she may offend them.
 - 'Keeping going' may mean different things. What does it mean for you?
- **4 I Look After Myself** Adam, a sociable independent 87-year-old man living in an inner-city tower block, takes pride in managing his medication routine in a way that fits with his active life. He draws strength from faith, friendships, and memories of his past. A violent assault leaves him deeply shaken and fearful of going out after dark. Following a hospitalisation he is now reliant on insulin and a dosette box—neither of which are his choice. Adam feels his autonomy is slipping away and longs to regain control over his life and choices.
 - Adam values having a full and active life, looking after himself and being independent. What is helping him maintain his independence? What is hindering him?
- **5 Is There Anything We Can Stop Today?** Alfie, who manages a large and long-standing medication regimen, leaves another GP appointment feeling disappointed not to have reduced the number of pills he takes. While collecting his dosette box from the pharmacy, he notices a big delivery of medicines and is prompted to think about a friend who doesn't take their medicines. He wonders how much this must cost the NHS. When he sees a poster inviting people to take part in a research study about reducing medications Alfie begins to question more openly which medicines he really needs.



- Medicines may carry stories. Alfie's hospital doctors told him his pills were for life. Do any of the medicines you take carry a story with them?
- **6 A Glimpse of the Future** Hanna has a complex medication routine and becomes unsettled when her familiar GP surgery is overtaken by the National Adherence Service (NAS), a mysterious organization that monitors doctors prescribing and patients' medicine use through advanced technology. After being summoned to account for skipping doses and following her own system, Hanna is confronted by officials demanding compliance. With her trusted GP by her side, she begins to resist the impersonal, data-driven approach and together they start to plan a way forward.
 - It is estimated that up to 50% of medicines prescribed for long term conditions are not used. Why do you think this may be?
- **7 Polluting the Planet** Tom, a retired lorry driver, is involved in a village rewilding project. At a community environmental group meeting, he hears his GP speak about the environmental and personal impacts of medicine overuse, prompting him to reflect on his own long list of prescriptions. Feeling curious and unsettled by an unfamiliar concept polypharmacy Tom begins to question the necessity of all his medications, He raises the issue of polypharmacy for discussion at the next meeting.
 - One cause of waste within the NHS is the prescription of medicines that are either not needed or not wanted by patients. How do you think doctors and patients might start to address this problem?

Project Overview

The aims of this project were to:

- operationalise these stories through the development and delivery of storytelling sessions in community settings
- evaluate the impact of the stories on how people think, feel and act about their medicines
- develop a facilitator guide to accompany the stories and enable independent delivery of storytelling sessions
- develop recommendations concerning what may be needed to scale and spread these stories nationally

Care City Innovation CIC has acted as the innovation and evaluation partner to this project. Care City is an innovation centre for healthy ageing and regeneration, based in Barking. Co-founded in 2013 by London Borough of Barking & Dagenham (LBBD) and North-East London NHS Foundation Trust (NELFT), it is now an independent Community Interest Company. Care City carries out research, innovation and development work to strengthen health and the determinants of health. This work is always in partnership with local people and local health and care partners, with a focus on local impact, national significance and the spread and scale of successful interventions.

This project was funded through a Queen Mary University of London Impact Accelerator Award.



Methodology

This section describes separately the methodologies for developing the storytelling sessions (and facilitator guide) and delivering the evaluation. The cohort for this project are residents of North East London aged 65+ who are taking 5 or more medications.

The delivery and direction of this project were overseen, shaped and supported through regular operational and steering group meetings with the QMUL team and external experts.

The operational group met on a monthly basis throughout the project and was attended by the City Team, Deborah Swinglehurst (QMUL), Nina Fudge (QMUL), Alison Thomson (QMUL) and Rachel Barnard (QMUL). Project progress and timelines were reviewed during these meetings, along with plans for the following month, and any challenges/barriers/risks to delivery. The group provided project oversight, review of methodologies, reflections on emerging findings and contributions to this report and the facilitator guide.

The steering group met every two months throughout the project and was attended by members of the operational group, Stefán Hjörleifsson (Associate Professor, Department of Global Public Health and Primary Care, University of Bergen), and Michael Naughton (Medicines Optimisation Lead for Tower Hamlets, NHS North East London Integrated Care Board). The group provided additional project oversight, methodological review and review of emergent findings from varying analytical perspectives. The group also provided advisory support regarding the positioning of this project within the context of local, national and international research, policy and practice.

Story delivery design and methodology

The development of the story telling sessions, advertising materials and the facilitator guide were carried out through:

- Discussion with, and input from, the Care City Community Board: 11 Barking and Dagenham residents who contribute their lived experience to Care City projects, and support links to local community groups.
- Meetings with the project Patient and Public Involvement (PPI) group: 4 residents of North East London meeting the cohort criteria who met virtually twice to advise on the development of the sessions
- The delivery of 14 storytelling sessions with 126 residents, 82 of whom met the cohort criteria:
 - These sessions took place in a variety of settings including community centres, libraries, supported housing, dementia hubs, and informal public spaces such as pubs
 - Sessions took place with both existing groups and specially convened groups, reflecting a wide range of participants, culturally and socially, and varied experiences with medication.



- Sessions ranged in size from 2-28 attendees (2-18 for those meeting cohort criteria)
- The average number of medicines that attendees were prescribed was 8.5, and the highest number was 21 (based on responses from 61 attendees)

Details of the 14 sessions can be found below:

Session ID	Setting of LTDAM session	Pre-existing group?	Number of eligible attendees
A	Community Library	No	4
В	Community meeting space	No	3
С	Community meeting space	No	2
D	Dementia Hub	Yes - Carer support group	6
E	Community space for older adults	Yes - Self management group	2
F	Dementia Hub	Yes - Carer support group	15
G	Community space for older adults	Yes - Dementia support group	10
н	Community space for older adults	Yes - Asian Older People's Group	18
I	Sheltered Housing	No	5
J	Pub	No	2
К	Sheltered Housing	Yes - resident social group	5
L	Pub	No	3
М	Pub	No	2
N	Not-for-profit housing association	Yes - resident social group	5

The sessions were used as an opportunity to test, refine and iterate both the facilitator guide and our delivery method. Each session was informed by structured planning but adapted dynamically based on setting, group size, and participant needs. Facilitators introduced the context for the stories, guided discussion using prompt questions, and observed both immediate responses and the nature of conversations that followed.

The sessions were facilitated by members of the Care City team with varying levels of experience with facilitation, and familiarity with the project. Early sessions were facilitated by two experienced facilitators who were also leading on the project for Care City. The reflections and input from these experienced facilitators were necessary to develop and carry out initial refinement of the sessions and guide (along with community board and PPI input). Later sessions were facilitated by operational staff from Care City (comms and marketing and business management) with little facilitation experience or prior knowledge of the project. This was to support the further refining of the facilitator guide and ensure it is suitable for wider use.



Examples of iterations to the guide and sessions through this process include:

- Modifying the icebreaker activity for pre-existing groups who were less comfortable sharing medication details with people they already knew.
- Tailoring facilitation styles to accommodate participants with dementia or limited English, including using bilingual group leaders where needed.
- Exploring different ways to present the stories (e.g. having a single reader for larger groups vs. reading in small groups) and testing the impact of these formats on engagement and discussion quality.
- Our facilitator guide, which we developed and refined through the course of the project, supported delivery across diverse settings and ensured a consistent structure while allowing flexibility. It includes detailed guidance on session setup, story selection, discussion facilitation, and a call to action to support post-session reflection or onward conversations.

Evaluation design and methodology

The impact of the LTDAM sessions was evaluated using a core set of questions prompting people to reflect upon their evolving thoughts, feelings and practices around medicines, subsequent to the session they joined. Within questions exploring changing medicine practices, people were asked to reflect on the social impacts of the session, including:

- Changes to medicine conversations with friends and family
- Changes to medicine conversations with healthcare professionals
- The "onward life" of the stories had they shared the stories with others?

The full set of core questions asked within these follow-up sessions are outlined in Appendix A. The format of these questions was adapted to suit different circumstances. For instance, within large group follow-ups, evaluation questions were translated into a series of answer statements on small cards (Appendix A). These were handed out to participants, who were asked to look over and choose from them, based on which statements they felt captured noticeable impacts upon their thoughts, feelings and practices around medicines since reading the stories. Participants were then asked to share with the group why they had chosen the specific statement. These responses as to why they had chosen the particular statement(s) formed the qualitative data which was then analysed for themes in combination with all other qualitative data.

As a secondary method, some participants were asked to share their recent thoughts or feelings about medicines with the aid of some creative picture cards. These cards showed stylised images of objects, people and scenes that people could interpret and use to express in a way that would be more accessible, inclusive and engaging, particularly in group-style follow-ups. These images were selected from a larger pre-existing deck of game cards designed to serve creative expression, and the set selected deliberately to be diverse in terms of emotion, affect and valence (positive versus negative). Participants were asked to pick a card that they felt captured something about their thoughts or feelings about medicines in the past two weeks, and to

share whether, and to what extent, these thoughts or feelings had been shaped by their experience of the LTDAM sessions. This exercise gave us a chance to surface any potentially important *longer-term* emotional or attitudinal impacts of, or more mature reflections on, the sessions.

A thematic analysis was then undertaken on data collected in the above follow-ups. Key themes pertaining to impact of the sessions drawn in follow-ups are outlined in the section Impact Beyond the Room below.

Of 82 people meeting criteria who attended sessions, a total of 49 (60%) were followed up with in some capacity as part of this evaluation:

- 1:1 Follow Ups n=10
- Group Follow Ups: n = 39 across two groups:
 - A group held in a communal space of a supported living accommodation (N=7)
 - A group held in a community library (N=32)

In addition to the above data captured, facilitators in LTDAM sessions took notes of live discussion within the sessions themselves, documenting the more immediate impact of stories upon people's conversations and reported intentions. The themes we derived in our analysis of these notes are shared in the Impact beyond the Room section.

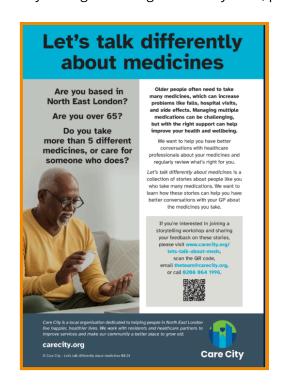
Results

The section reports separately the results of the process of developing the storytelling sessions (and facilitator guide) and the results of the evaluation.

The process of session and guide development

Recruitment and advertising

An initial step of the project was to develop, with input from the Care City Community Board, a recruitment leaflet for the project. The original intention was to build a database of interested residents meeting the project criteria with whom group sessions could then be organised. The first iteration of the leaflet can be found in <u>Appendix B</u>. The distribution of 1000 leaflets in the first printing was completed by October 2024. The leaflets were placed in community settings including community hubs, pharmacies, and libraries.



Feedback on the initial recruitment leaflet highlighted several barriers that may have influenced willingness to participate. Some potential attendees were unsure whether they met the eligibility criteria, with confusion about what "taking five or more medications" meant, particularly for those on irregular regimens or medications taken weekly rather than daily. Others expressed discomfort with the idea of joining unfamiliar groups or travelling to new locations, especially those with caring responsibilities or limited social confidence. Carers in particular noted feeling unable to relate to others who did not share their experiences. Practical challenges also emerged, with some people feeling too stressed or overwhelmed by daily life to attend, or unsure of their availability from one day to the next. A degree of apathy or fatalism was also present, with individuals unsure how to talk about their medicines, uncertain about the relevance of the session, or doubtful that it would lead to any meaningful change. Underpinning many responses was a deeper fear: a

reluctance to question medication regimens despite having concerns about them, due to not wanting to offend or challenge healthcare professionals.

This feedback informed both further iteration of the recruitment leaflet and initial development of the sessions. Key learnings from this feedback were:

- Scope/Gatekeeping:
 - The sessions could be open to all, not just those meeting the project criteria, in order to encourage attendance (and maximise opportunities for impact).
- Demands of additional travel/unfamiliar groups:
 - The sessions could be a part of people's existing groups and be held in places where they regularly go.
- Stress/Apathy/Fear:
 - o Provide more context in advance about what the sessions are and are not
 - Ensure drinks are available during the sessions.

Based on this feedback, input from our research colleagues at QMUL and dedicated sessions with both the project PPI group and the Care City Community Board, a second iteration of the recruitment leaflet was produced which was distributed through an additional print run and online channels, including Care City's LinkedIn, where we encouraged our network to share with those that they thought may be eligible and interested in taking part, through Care City's BlueSky channel and through Facebook community groups.

Most of the changes occurred to make the leaflet more conversational, remove phrases that might make people question if they qualified to attend, and move away from what could be seen as 'NHS language.' The revised leaflet can be found below:



These recruitment efforts resulted in 15 people registering interest in the project which translated to 9 people (all meeting project criteria) attending the first 3 sessions. The capacity and resources required to deliver



specifically convened sessions to 9 people informed the ongoing approach of the project - to deliver the sessions within existing groups or in social settings that people already attend.

These groups were identified through Care City's existing community contacts and through approaches to relevant organisations with whom they did not previously have a relationship. Relevant organisations were those which held existing meetings for older adults and/or long-term condition support. Approach was made via email to the meeting organiser giving a brief overview of the session and requesting a place on an upcoming agenda. And posters were provided for each organisation running a session ,quoting the date and time of their workshop(s).

As we learned more about the delivery of these sessions we made sure to stress during initial contact that these were storytelling sessions and there was no clinical input or medical advice being given during the sessions.

Additional sessions were run in more casual community settings (two sessions were run in a pub). Through casual conversation with older adults attending the pub the facilitator introduced the project and arranged sessions in the same setting.

Implementation and developing the facilitator guidebook

The facilitator guidebook for *Let's Talk Differently About Medicines* (LTDAM) was developed through an iterative and practice-based process, informed by our experiences of delivering 14 sessions. Rather than designing the guide in advance and applying it unchanged, we refined it session by session, based on what worked, what didn't, and what participants told us along the way.

Sessions were hosted in a range of settings — including sheltered housing schemes, community centres, dementia support groups, and informal venues. Participants were diverse in terms of cultural background, health experience, and familiarity with group discussions. Some groups knew each other well; others came together for the first time specifically for the session. This variety allowed us to test the delivery approach with different group dynamics and adapt the guide accordingly.

Key Adaptations and Learning

- **Flexible session openings**: We initially used a structured icebreaker where participants rated their confidence talking about medicines. While effective in some groups, others, particularly long-established ones, interpreted this as an invitation to share personal information about their own medicines and felt uncomfortable about this. We responded by creating a range of gentler opening prompts, giving facilitators options depending on the setting and group tone e.g.:
 - What brings you joy? "Can you share one small thing that's lifted your spirits recently?"
 - Getting to know you: "Tell us your name and something you enjoy—like a hobby, a place, or a favourite snack."



- **Group formats and story selection**: We experimented with various formats, including reading stories aloud in large groups, using small break-out discussions, and letting participants choose stories that resonated with them. Participants often identified strongly with the characters and themes, and this emotional connection shaped the depth of discussion. The guidebook was updated to help facilitators tailor story choice and discussion questions to the needs and experiences of the group.
- Clarifying the purpose of the session: Some participants arrived expecting a medical review or
 professional advice. We quickly learned the importance of clearly setting expectations from the
 outset. The guide now includes clear introductory scripts that emphasise the non-clinical,
 conversational nature of the session focused on sharing experiences and reflections, not individual
 health advice.
- Supporting facilitators in real-time delivery: Sessions often touched on sensitive or complex issues. Facilitators needed practical strategies for managing emotionally charged moments, uneven participation, or questions about clinical matters. The guide now includes guidance on recognising those strong feelings, making space for them, and helping people feel less alone with them. The facilitator guide now also stresses that it's not the role of the facilitator to offer advice, and it's important that they are completely clear that they are not there to guide people on what medications they should or shouldn't take, nor to tell them what to do
- **Cultural and language considerations**: In multilingual or culturally diverse groups, we saw how delivery could be made more inclusive by involving trusted community figures or adapting how the stories were presented. In a large session (N=27) held with an existing 'Asian Older People's Group' attendees were split into 5 smaller groups for the reading of the stories in **two of these** groups, **the story was** read aloud in Gujarati by group leaders, with strong engagement as a result.

Each session added to our understanding of how the LTDAM stories can spark meaningful conversations — and what facilitators need to create a space where people feel safe, heard, and empowered. The resulting guide is both structured and adaptable. It provides practical tools and templates while encouraging facilitators to use their judgement and respond to the group in front of them.

The process of session delivery identified key barriers and facilitators to their delivery which further informed development of the guide.

Barriers to delivery

1. Logistical Barriers

• Scheduling and Attendance Challenges

Sessions were occasionally cancelled or had low attendance due to health issues, holidays, or last-minute dropouts. In some settings, such as the dementia hub and pub-based sessions, the makeup and size of the group also made it difficult to maintain engagement.



• Lack of Consistent Clinical Engagement

Participants often expressed frustration that they rarely saw the same GP or had limited opportunities to discuss their medications, which influenced expectations for the sessions and affected follow-up conversations after sessions.

• Venue Suitability

Some spaces were not ideal for facilitation (e.g., sessions held in pubs or large rooms without breakout areas). These settings sometimes made it hard to hold focused or inclusive discussions, particularly for larger or more cognitively diverse groups.

• Resource Limitations

While physical story booklets and refreshments were provided, the facilitation sometimes depended on one individual. In sessions with larger groups, single facilitators struggled to manage discussions, answer questions, and support individuals simultaneously.

2. Relational Barriers

• Group Dynamics and Disclosure Comfort

In pre-existing groups, especially where people knew each other well, some participants were reluctant to speak openly about personal medication issues. Icebreakers involving medication counts occasionally fell flat or caused discomfort, leading to necessary adjustments in approach.

• Expectations of Clinical Advice

Some participants misunderstood the purpose of the session and expected medical guidance or personal medication reviews. This sometimes created confusion or disappointment when it became clear the sessions were for discussion and reflection only.

Facilitator's assumptions

Facilitators reported sometimes avoiding certain stories or making choices on behalf of the group because they believed they might react poorly to certain themes of a story or not identify with their characters. There was no evidence to support these assumptions, and the facilitator guide was updated to discourage facilitators from making these assumptions on behalf of a group.

3. Contextual and Structural Barriers

• Systemic Frustrations with Medication Management

Many participants shared negative experiences of repeat prescribing, poor communication from GPs, missed reviews, and being unaware of why medication changes were made. These systemic issues often dominated the discussion and highlighted the emotional burden of navigating polypharmacy.

• Cultural Hesitation to Challenge Authority

Some older participants expressed a generational tendency to "do as you're told" and felt hesitant or even afraid to challenge medical decisions. This cultural norm created a barrier to the kind of open, reflective conversation that LTDAM aims to foster.



• Language and Literacy Considerations

In linguistically diverse groups, the stories sometimes required translation. Although community leaders stepped in to help (e.g., reading stories in Gujarati), this required additional planning, and support was not always available.

Facilitators of delivery

1. Co-Design and Iterative Development

Ongoing refinement through lived experience

The facilitator guidebook was not static and evolved in real time based on what was learned in each session. Feedback loops between facilitators, participants, and co-design contributors (including the project PPI group and the <u>Care City Community Board</u>) helped ensure the materials were practical, relevant, and responsive.

• Input from people with lived experience

Early involvement of older adults and those managing polypharmacy in shaping the format, tone, and materials helped ensure cultural relevance and emotional resonance.

2. Flexibility and Responsiveness

• Adapting session structure to group dynamics

Facilitators were able to modify the format in real time — choosing different icebreakers, adjusting group sizes, and changing how stories were presented (e.g., read aloud by a participant or in small groups). This flexibility helped maintain engagement even when challenges arose.

Customising story choice

Stories were selected or offered in ways that connected with participants' lived experiences, which created emotional resonance and deeper discussion. Participants often identified with characters facing similar challenges (e.g., medication burden, autonomy, or trust in clinicians).

3. Skilled and Sensitive Facilitation

• Use of open, reflective facilitation techniques

Facilitators created a safe, respectful environment where participants could express both practical frustrations and emotional experiences. The emphasis on listening, curiosity, and shared reflection helped build trust and participation.

• Emphasis on non-clinical space

Clearly framing sessions as non-medical and discussion-based helped reduce pressure and make room for emotional and narrative contributions, rather than fact-checking or clinical problem-solving.



4. Community and Peer Support

• Use of trusted community settings and leaders

Sessions held in familiar venues, such as community centres, sheltered housing, and dementia hubs, supported participation feeling less intimidating. In some sessions, bilingual leaders or known facilitators helped increase trust and accessibility.

• Peer-led reflection

In several sessions, participants began informally supporting one another — sharing tips, voicing common concerns, and reflecting on shared experiences. This peer-to-peer exchange was powerful and helped shift the tone from passive information delivery to active engagement.

5. Quality of the Stories

Authenticity and relatability

The stories themselves — based on real experiences and carefully crafted — were seen as a major strength. Participants described them as "relatable" and said they helped them see their own situations differently or gave language to feelings they hadn't been able to express.

• Emotionally engaging and discussion-provoking

Stories raised themes such as autonomy, frustration, and trust in ways that were non-confrontational but thought-provoking. This helped initiate reflective conversations that often extended beyond the session.

The impact of story delivery

Findings about the impact of the LTDAM sessions are shared here in two sections.

The first section unpacks the impact of the stories "in the room" and captures insights and personal stories shared during the sessions themselves, based on live discussion notes taken by story facilitators. This section gives some indication of the potential of the stories to provoke specific kinds of immediate conversation.

The second section speaks to longer term impacts "beyond the room". This section traces how taking part in the sessions prompted conversations, feelings and actions in broader social and personal settings, in the weeks and months following attendance (see "Evaluation Design and Methodology" for more details on timescales here).



Impact 'in the room'

Below we present key themes within conversations prompted by the stories within the LTDAM sessions.

Confidence in talking to GPs about medicines is very mixed, and often depends on good long-term relationships

Many participants were prompted by the stories to remark on similarities with their own experiences. Participants shared accounts of their own interactions with GPs around medicines, with many describing specific conversations they've had to interrogate the impact of medicines or request stopping medicines. Participants displayed mixed levels of confidence in having these conversations. Those who expressed high confidence talking with their GP about medications tended to be those who had good long-standing relationships with their GP, who understood their medical history.

"I feel very confident [in having medication conversations]. I love my doctor and have been with her for years. We have great chats, and she has really helped me with my allergies by giving me a nasal spray on top of tablets. I've had her for donkey's years and she's good. If I have someone else, I can't talk to them like I do her." - Participant, session L

"I had problems previously with statins and now the one I have does its job. We had to weigh the benefits against the side effects. But I have a good relationship with my doctor, and that seems to be down to luck compared with others." - Participant, session L

"It was good when we just had the family doctor. If you see the same one, they aren't relying on having to read through all your notes or having to repeat yourself. It feels like you are getting the personal touch" - Participant, session A

Meanwhile, those expressing lower confidence often pointed to constantly changing relationships with medical professionals or the lack of time and opportunity available for sustained conversations. As a result of this, a number of people shared a preference to go to other professionals with more time and patience, including pharmacists and opticians.

"I last saw my GP when I needed a blood transfusion, but I have lost confidence in the GP and having a good conversation. I now go to the opticians for my eye drops." - Participant, session L

People want to reduce medicines, often fearing drug-drug interactions and side effects, but are hesitant to challenge their GP and encounter procedural barriers when attempting to do so



While some participants talked about the positive impacts of medications, and being thankful for their GP "keeping them alive" a significant number of people shared a fear that they were on too much medication, a desire to reduce that, and displayed a keen awareness of possible side effects and interactions between medicines.

"If you mix up the tablets and take them together, then effectively you're taking another medication." - Participant, session K

"Doctors are not aware of the side effects. Anxiety meds can cause glaucoma - there's no awareness" -Participant, session B

However, many people perceive their GP as an authority figure or expert who they are afraid to challenge. Comments on this have touched upon the time pressures GPs face, which on the one hand makes people worried details are missed, while on the other makes people hesitant to add more workload by making additional requests:

"The GP has status so I'm afraid to challenge them. They are quick to write a prescription without checking and properly understanding what the meds are for." - Participant, session H

"I would like to reduce them. I don't, though, as they are the experts and it would give them more work." - Participant, session F

"The doctors are there for my benefit - I shouldn't have to feel worried. [But] it can be scary to raise something and GPs bark back. Other older people might hold back and not speak up." - Participant, session B

A number of participants shared their attempts to create conversations around medications, while facing process or time barriers to doing so, which was frustrating.

"I complained about being triaged by reception and I wanted to talk about meds to GP only - it's really wrong" - Participant, session F

"It can feel futile to even have a conversation - you're not being listened to" - Participant, session B

People worry about running out of medications but can find it difficult to renew prescriptions, so justify stockpiling.



Many participants related to stories portraying difficulties in securing sufficient supplies of medicines, and the anxiety around running out. While many people recognised that this could lead them to overstock, which GPs advise against, they felt this was justified:

"When my medications are out of stock, I panic" - Participant, session J

"We are all the same and want to keep our medications and I am keeping some. We are all guilty of that - we like to keep one step ahead. As it's free, I tend to order more and ensure I have enough." - Participant, session J

Participants also reflected on the difficulties of renewing prescriptions, especially for some older people who are less digitally literate, with lots sharing advice with others present in the sessions about how to ensure they don't run out of medications.

Medication reviews are rarely offered, and people feel the health system is not geared up for proper medication monitoring.

Many people expressed concern that they had not been offered medication reviews and expressed surprise that GPs aren't held responsible for this, fearing they may not do enough to pick up on medication interactions for new patients.

"To me, the story highlights the main concern - GPs never review medications or get to the root of the problem. GPs should have a legal responsibility to review people's meds. Chemists profit from this." - Participant, session |

"There is a lack of experience in the GP. They just prescribe and send you away. When you're on medicine and a new patient to a GP, the GP and pharmacy should find out how you are getting on, not wait for you to return. Doctors aren't looking at interactions - even asking "why are you on those two meds together?". If you're on new meds, you should go back and tell how you are getting on - GPs don't have the time" - Participant, session |

Some participants pointed to poor record keeping and data sharing between healthcare professionals as contributing to this challenge

"If [GPs] don't have records, then they won't ask." - Participant, session I

"They have records, but it can take a while for consultants and GPs to chat and update the system." Participant, session |



People often see pharmacists as a preferred source of medication advice

Perhaps as a result of the above challenges with GPs, many session participants spoke of their likelihood to go to pharmacists as a default source of advice. Generally, people shared favourably about the greater time and patience pharmacists had to discuss medications, though others were still concerned about medication interactions being missed.

"My chemist is helpful, so I feel confident talking about medications," - Participant, session I

"I listed the symptoms and said they are no good, so the pharmacist suggested I changed them - [it was] all very easy" - Participant, session |

"I went to the pharmacy for advice and was given meds, but they didn't go through allergies or [if I was on] other meds." - Participant, session B

Impact "beyond the room"

The themes in this section are those derived from the analysis of follow-up conversations exploring the longer-term impact of the stories on people's thoughts, feelings and actions. More details on this approach can be seen in Evaluation Design and Methodology above, while core questions asked to help surface this data are given in Appendix A.

Of the long-term impacts of the stories surfaced in this research, two came through most strongly. First, a significant number of people described an impact that went beyond having different thoughts and feelings, towards active steps they were taking to effect change. Second, the session had prompted many participants to also reflect on the ways that we might work together as a community to help people manage or reduce their medications.

In the following section we set out our findings relating to these longer individual changes and also to the social impact of the story-sharing sessions.

Impact upon individuals' medicine practices

As a result of engaging with LTDAM sessions, a number of participants shared that they had chosen to ask questions and raise challenges about the medicines they'd been advised to take, when interacting with healthcare professionals. This could mean challenging advice from individual healthcare professionals, or challenging issues relating to the process of prescribing



Participants have questioned and challenged healthcare professionals' advice

One woman we followed up with decided to question her GP about her tablets after thinking more about their possible side effects, which led to her taking the decision to reduce from daily medication to just three times a week:

"After thinking about side effects, I questioned my GP about my cholesterol tablets making sugar levels go up. Talking [in the story session] helped me take control of what to do. I said [to my GP] I'd take only three days a week - the talk empowered me to challenge my GP to ask about taking it every day. Now I'm feeling better - I've noticed a difference in my health." - Participant, session F

Another participant mentioned having spoken with her GP about coming off medication since the session. In this case, the medication was not changed, but she wishes to keep that conversation alive:

"I have been on Omeprazole for 20 years and I have asked the doctor to come off it, there's lots of side effects with it and been told I can't, but I would like to have that conversation again with her." - Participant, session M

People have been picking up on what they see as problems in the process around prescriptions and gaps in the system

Other participants shared more about having taken steps to challenge what they saw as problems in the wider system around prescriptions, attributing this to discussions in the LTDAM sessions:

"Some of us have been on the same drug for years and years. All of us think doctors are gods and take their words for it. But when I went to the clinic yesterday, I realised that my GP surgery hadn't been responding to an issue. It appears something got lost, so I complained that they weren't following up properly. The [LTDAM] session made me more aware of imperfections within the system - a lack of joined up thinking between hospital and doctor - they don't realise there's a clash." - Participant, session H

"In January I found out I was given a prescription but didn't know about it. I got a phone call saying I should have had something a month ago, so I raised a complaint when I didn't get it. It's only vitamins, but it could be a major tablet and I've gone a month down the line without knowing anything about it. I most probably wouldn't have done this a year ago." - Participant, session A



People have taken active steps to reduce reliance on medication

The challenges outlined above include cases where people are pushing both for and against *specific* medications, but more broadly after attending a LTDAM session, a number of people shared active steps they'd taken to try to cut down the overall burden of medication. Most often, this was done in consultation with a person's GP:

"[Since the session] I asked for a medication review - it didn't reduce the overall number, but the dose was reduced." - Participant, session F

"I have cancelled one of my prescription medications." - Participant, session M

One person shared how the session prompted her to pick up on an issue with statins that she had long been meaning to address:

"Why my GP didn't stop the statin, I don't know. The GP didn't know why the consultant gave me two. I said, "I will stop taking statin and have a blood test and see what happens". But I didn't do anything. Then after chatting with [the LTDAM facilitator], I stopped taking the statin and then did my research on whether I should stop others." - Participant, session C

The participant quoted above shared how the research she did after the Medicines Talk session put her on a quest to take control of her own health. The extended quote below nicely illustrates how she has been prompted to begin a longer journey to cut down on medications, acknowledging the risks, benefits and challenges involved in doing this appropriately:

"From the end of March, I started walking every day and swimming every week. "I have to do something myself too", I said [other than just stopping medicines]. When I did more research, I realised nothing happens overnight like a miracle, so I thought I should keep other [tablets] going. I am going to have a blood test at the end of May and every day I am doing my swimming so I can have a good blood test. I want to work hard. I will also have a liver scan in that week [so] I will know where I stand. I've stopped the statin, but the pharmacist said if cholesterol level doesn't go down you have to go back. I thought "one at a time". I don't want to scare my body, so [the] next is about my blood pressure medicine. I thought "let's do the cholesterol tablet first". I have a hope and dream that I will win - we'll see. I can come off. The blood pressure tablet is the next one to tick off. It takes years to get diabetes too [which I have in early-onset form] so you have to wait a while with hard work - don't expect [it] overnight if [it's] so many years to get it - gradually [it] will change hopefully" - Participant, session C

The focus on incremental steps and broader strategies for managing health, illustrated in the above quote, also came out as a theme in people's thinking post-session, and is drawn out in more detail in a later section.



Some participants are more inclined to dispose of medicines safely

Another important issue identified by people who'd attended was a greater propensity to follow the recommended steps for disposing of medicines correctly.

"What stood out was how to get rid of the leftover medications - I felt I understood more about how to do this. I talked to my pharmacist, and they would do this for me. Since then, if I think anything is out of date and not on prescription any more, I'll send it back." - Participant, session H

"I took unneeded medications to the pharmacy, but they didn't have a bin - I asked where the medicines went." - Participant, session H

"Electronic prescriptions are repeated so it's easier to end up with every tablet on the list even though they run out at different times which causes waste and can end up stockpiling, when some of the meds have sell-by dates. It made us more mindful from listening to the story. I have seven items and now I work out when I need them, so split the prescription into two so they aren't going out of date and I'm not wasting the medicines. I keep a month's supply." - Participant, session M

People are having new conversations about medicines, feeling driven to raise awareness, and some of these are already having practical outcomes.

A number of participants shared that they were "having more" or "having different" conversations on the basis of the session, which we can see as a form of social impact. Often this meant discussing possible negative effects of medications or problems in the system with friends, whilst being cautious to avoid being seen to "offer advice".

"I mentioned the session to one to one or two people, and about medicines in general, sharing my experiences and also some of the dangers. But I wouldn't want that to have bad effects on them [through their] not taking [it]. We just go "hmm", because you don't want to make any comments and say you shouldn't take [them] because if they stop and get more problems it's your fault!" - Participant, session B

"If people tell me I don't take medications, now I say "great!" - Participant, session C

"I talked about some friends that have been on long term medication and their concern that it's never reviewed." - Participant, session M

One participant shared how she has talked about the session with a friend, who subsequently set up a chat with her own GP for a medication review:



"I have also spread the word to my friends and colleagues. One said, for the last 25 years I have been taking cholesterol tablets and there is lots in the paper these days [saying I may not need it] - the world has moved on and there is lots of new research. She said I will book a chat with a GP, ask why they haven't discussed medicine - "do I still need it?" and then she will tell me." - Participant, session C

Another participant shared how the stories prompted them to reflect on and talk about how one family member had managed their medicines and how this reflected their broader approach to their health:

"We discussed [my partner's] mum who had passed some years ago and how she didn't really talk about her medication and was very stoic in her approach to long term conditions" - Participant, session M

Other participants had met as a group again to discuss medicine interactions, having done some more research independently:

"We subsequently had a chat about turmeric and whether it interacted or interfered with medicines on the basis of the session. We researched it ourselves" - Participant, session H

In a similar way, another group of participants said that they enjoyed the session so much that they took the LTDAM story booklets and ran another one independently.

In summary, coming together to read the stories has provoked a range of both 1:1 and group conversations outside of the sessions.

People are noticing more about other people's medicine practices, and the lack of support they have

Often as a precursor to the above conversations, many people we followed up with spoke of a heightened awareness of their friends and family's behaviours around medicines, noticing things they may have overlooked before. They were particularly concerned about those who they knew were on long term medications but not having medication reviews.

"I think, why do you keep taking the medication - it's a waste of money." - Participant, session A

"I'm more aware of people having meds without asking more about them and their side effects, and people not having reviews - I always advise them to have a review or suggest they go back to their doctors" - Participant, session M

One participant, who we followed up alongside her husband who'd attended the LTDAM session with her, commented that she's since noticing more about some of her friends' tendencies to dwell in their health problems, and considering how best to support them:



"I've noticed more about people wanting to tell me everything that's wrong with them. I had a chat yesterday. Whenever I speak to [this woman] there's always something wrong with her. I let her finish telling me the whole story and then tried to be a bit more chatty and generalise more because she does dwell and I don't think it's good for people - sometimes you can help just by listening but not be dismissive" - Participant, session B

Impacts upon thoughts and feelings around medicines

In addition to changes to medicines practices and wider social impacts of the sessions, our follow up sessions also asked people about their more recent feelings and emotions around medicines, and how those may have shifted since taking part in the LTDAM sessions.

People have felt more confident to challenge healthcare professionals and consider how they might achieve greater agency over their health

Many people expressed the impact of the LTDAM sessions in terms of "growing their confidence" in their interactions with medicines and healthcare professionals. Some shared this in a direct and general sense, while others spoke to past or hypothetical situations in which they reckoned they would act differently now. This suggested a shift in their dispositions towards medicines and prescribers, though they may not yet have taken any specific action since the session.

"My confidence in talking to healthcare professionals has gone up." - Participant, session F

"Now, I will pick up and challenge the doctor." - Participant, session K

"A long while ago, I knew someone who was given medication, but it was someone else's prescription but when they went back, they said, "it's only a heart tablet so you can take it". This was a couple of years ago. If I saw this happening now, I'd advise them to go back to the GP - don't just take the pharmacist's word for it even though they're very experienced. I most probably wouldn't have thought much about it back to them. Now, it's a bit of a "shock horror" - how can they tell someone to take someone else's medication!?" - Participant, session A

Linked to this, other participants shared that the LTDAM sessions had given them a better sense of agency over their personal health and the role medicines might play in that.

"It made me think more about the control you have over your health and wellbeing." - Participant, session K



One participant shared this change in terms of feeling empowered to listen to her own body, and use that as a guide for whether or not to be taking medications:

"[Since the LTDAM session], I feel better able to have a conversation that supports my health and life priorities. I think we're not given enough credit that we know our bodies. You're a passive person and they just write a prescription. [But] I think there has to be a proper conversation about your health and what you feel your priorities are. Like with diabetes, there are programmes for prediabetes. Similarly, there should be more preventative stuff [around medicines]. There is too much emphasis on getting the medication, and pharmaceutical companies making money" - Participant, session F

A different participant shared how the sessions made her think differently about which healthcare professionals are best placed to help her in maintaining her wellbeing and about her personal responsibilities around this.

The potential negative impacts of taking and not taking medications have stood out to people, alongside questions about the ability of medicines to meet their own health problems.

As a secondary part of LTDAM follow-ups, we asked participants to pick from a series of visual cards to capture anything that felt important about how they'd been thinking or feeling about medicines over the last two weeks, and to then share whether or not those thoughts or feelings had been shaped in any way by the LTDAM sessions.

This exercise gave us a chance to surface any potentially important *longer-term* emotional or attitudinal impacts data of the sessions, as opposed to immediate responses within or just after the sessions, and which might have been directly linked to changes (or attempted changes) to their medicine practices since the LTDAM sessions.

When completing this exercise, it was striking how many people picked out cards that express *negative* thoughts and feelings about their medicines.

For instance, one participant chose a picture of a card showing a robot, saying that this captured how her medications were making her feel "clonky" recently. Another chose a card with a train it on, comparing it to the feeling of being on a rollercoaster:

"This [medication] is making me feel like you're on a rollercoaster. I'm aware this can happen for people"
- Participant, session A

While most people who shared these negative feelings about their medications did not explicitly attribute them to the LTDAM sessions (by saying for instance that they had *become more aware* of these side effects since the sessions) some people did share experiences that aligned closely with some of the issues that were discussed in the LTDAM sessions. For instance, one participant used a card to express how her medicines



were giving her uncomfortable side-effects, but that she felt "trapped" into continuing to take the medicines, thanks to unhelpful responses from healthcare professionals when she had broached the topic of coming off the medication. Other people also spoke to a similar concern in follow-ups about the challenges of *knowing* it might be good to come off medications, but being frustrated when they attempted to act on that knowledge:

"For me, I still have to take a lot, but you don't want to - I feel like I'm trapped into having to." Participant, session K

"If you speak about not wanting to take them, doctors immediately start talking about the potential dangers of this" - Participant, session K

"I have blood pressure and cholesterol tablets. With the blood pressure one, the doctor scared me saying you might have stroke if you come off - I wish my GP would have helped me" - Participant, session C

The prevalence of negative associations with medications that were expressed in this exercise is a reminder that interventions that raise awareness about the potential risks associated with multiple medications need to be delivered sensitively. For some people there may be little or no scope for changes to medication regimens but sharing concerns about this may open up other possible avenues for support.

What *is* clear is that many people came out of the LTDAM sessions with a keener awareness both of how much they were taking, the potential of those medicines to multiply, and the potential for negative side effects and risks associated with those practices, even if they didn't want to take as much as they were being prescribed:

"The last session made me aware of how much I was actually taking." - Participant, session H

"What was shared was really close to my heart as I don't believe in medicine. The doctor gives you one medicine then each time you go back you get number two and number three and so on." - Participant, session C

"[My husband] has since checked the side-effects of all the tablets we take." - Participant, session B

"I'm confident in what I'm taking, but I wish there wasn't so much of it." - Participant, session B

Two separate participants noted how some of their present concerns around medications stemmed from a worry that medications weren't sufficiently personalised.



"When [I was] researching blood pressure, they all say, "stop alcohol, reduce weight, stop smoking and that". But I do not have that weight. I'm only 50kgs and I don't drink because that's my religion. So, I'm thinking that my GP has given me standard blood pressure tablets that would suit someone 100kg or [someone] who smokes. But that standardised level might not suit me. They don't look and think "this person is not obese, doesn't drink" - why is it standard?" - Participant, session C

"[Recently, a friend of ours] talked about how he had lost weight and then was falling over loads because the tablets hadn't been adjusted for this weight loss over the past 6 years. When he ended up in A&E they said he was on too much medicine for a man his size about 3 months ago and that he needed to go to the GP and ask them to review them thoroughly. He said the reduction had helped with the falling over." - Participant, session L

The participant who shared the first quote above noted that she'd been looking for advice since the session on how to reduce medications safely, and whether her conditions could be reversed, however she hadn't found anything useful. Given the likelihood of LTDAM sessions raising awareness of the potential negative impacts of taking multiple medications, and the probability that others will follow-suit in looking for advice on how to reduce, it is important that facilitators manage expectations and acknowledge that for some people this may be difficult or impossible; they may not always get what they hope for from a conversation with a health professional.

Some people have expressed a desire to take more active steps to improve their health, based on knowing their own bodies

Follow-up sessions revealed that multiple participants were reflecting on the need to take greater control over their health. Touching on earlier comments of one participant that she felt more empowered to listen to her body, others reflected on the importance that we do this on a collective level and a need to take more active alternative steps based on this:

"[Referencing a picture of an overflowing mailbox] This makes me think of overflowing pills. It's an indication to your body that you need to be more active in maintaining your health." - Participant, session H

"We know our bodies so ask questions rather than expect medical professionals to make all of the decisions. Rather than wait to be given, be more proactive." - Participant, session F

"I have a group of friends who say the GP doesn't change anything [around their medications] They all have diabetes. They are doing everything, but they don't know if that can come off the pills [...] They said if you take the tablet and exercise you will be well, but no one is advising them how to get off the tablet. I have taken my own initiative that just to come off on its own is not good, but you have to do something else as well - exercise. There was a problem and that's why you've got the medicine - we have to try hard ourselves [to get off it]" - Participant, session C



Sparking ideas for social action on medication practice

As seen in the above data, follow-ups to the LTDAM sessions revealed a growing orientation amongst some participants not just to reconsider their own medicine practices but also the need to consider those at a broader, societal level. Many participants shared that they had been moved by the LTDAM sessions to consider different practical ways that we might work together as a society to help people manage or reduce their medications. The three biggest themes within this are collected below as a series of "Participant Recommendations" and they capture some of the ideas that participants had considered since the LTDAM sessions, to move society towards a less medicine-reliant future.

It's worth acknowledging that some of these ideas may have been generated 'in the moment' by the discursive nature of group follow ups, and hearing other people's suggestions. Though many people shared explicitly that they had been thinking since the session on this topic since the LTDAM sessions.

Participant Recommendations

We'd benefit from raising awareness about alternatives to medicine.

One recurring suggestion within follow ups was the desire for communities and healthcare professionals to do more to raise awareness of other routes to maintaining good health beyond medications (and which obviate the need for those medications). One participant shared that she was prompted to think about this as the LTDAM sessions presented the first time she'd heard it may be feasible to come off her medicines:

"This was the first time I heard from [the facilitators] that there is a choice of whether to come off. But you have to not rush things. You have to take responsibility. There's no miracle. Every individual has to do it, and if you can spread the word - cinema, documentaries - we have to spread awareness in society." - Participant, session C

Others spoke about the importance of promoting exercise as a route to maintaining health:

"Doctors are talking about doing a lot of signposting, but whether they could signpost people to little walking clubs and companionship clubs for medication... [I don't know] Maybe a doctor should sign people up to social prescribing regardless, so that when they come in with things a social prescriber can talk to them about alternatives to medications if they don't want them?" - Participant, session A

"One medicine has side effects, and in order to tackle those side effects a GP may prescribe another medicine. But if we can share information altogether, we can talk about how we might exercise, to reduce risk, and financially can reduce the burden [of paying for medications]" - Participant, session F



One participant also talked about the value of socialising as a boost to health, pointing out that the conversation and interaction between the two women in Story 3 ("Keeping Going") was potentially just as helpful as changes to medications themselves:

"In the story, the interaction between two women helped them most of all. That personal interaction was all part of the benefit - the social part is something important. Scrabble is a therapy - interacting with other people is important - I'm not well most mornings and it gives a nice distraction. [...] Socialising really boosts you up - it's the best medicine" - Participant, session B

On three separate occasions, participants also raised the topic of placebos, and shared that they had questioned to themselves how far we might get the same benefit purely by *thinking* we have taken our medications:

"In one of the booklets, they talk about placebos so I was thinking why can't we all be truthful. I remember when my dad told me about grandma and her Parkinson's a long time ago. He said he couldn't find medicine on the right day and my grandma was really shaking, so [at] that time, in the country he was in, he made up something and he said I've got a better medicine; have it (it was water and sugar) and she stopped shaking." - Participant, session C

"It made me think of a GP prescribing placebos and after two weeks patients said they felt much better - sometimes medication helps just with the mental side - Participant, session F

"I also wonder how much these people give placebos out. I only went on medications because of a doctor saying high blood pressure and cholesterol. I would query but take their advice, but I wonder if they sometimes give a sugar tablet. If they think a lot of it is in your head. If I was taking a placebo but didn't know, would I be as good as I am anyway?" - Participant, session A

Clarity is needed on who should initiate medication reviews

The second big theme in participants' suggestions concerned medication reviews. A range of people shared that they would value more proactivity from healthcare professionals in offering medication reviews, and that they were often unsure why that wasn't already a professional responsibility or whether they themselves needed to initiate that conversation.

"I want more space to talk about it - I would value an offer of a conversation about it from the doctors" -Participant, session K

"I have to ask if the medication is still relevant" - Participant, session F



"The moment you say "review", they say go in for a blood test. It made me aware that it is very reactive. I have to push for it when they should. I have never seen a doctor say you don't need this medicine. If you're on 5 they want 7, they aren't going to reduce anyone." - Participant, session H

"Get doctors to be realistic about reviews. Are they contacting me or is it the other way around? It needs to be clear" - Participant, session M

"Despite their being a medicine review date on the record, the review never happens" - Participant, session C

Relatedly one person said it ought to be the GP taking the initiative to check for medicine interactions.

Guidance would help people prepare appropriately for medication review appointments

One participant suggested it may help telling people to take a friend with them to an appointment if they weren't confident to talk about reducing medications on their own. Another participant suggested advising people to make a list up front of what you want to say, and booking a double appointment to make time for it:

"The moment you walk into surgery, and someone asks how you are, you immediately forget. You can write it on paper - what to ask about. You start talking about point 1 and then the doctor says, "I don't have time for them all". You have to make a double appointment" - Participant, session F

This touches on the observation noted above from another participant that she didn't know where to look for advice about reducing medications subsequent to the Medicines Talk session.

Recommendations for scaling

This evaluation of *Let's Talk Differently About Medicines* (LTDAM) demonstrates that these stories offer a compelling and meaningful way to open up conversations about medicines. Their emotional authenticity, and narrative approach fill a gap that more traditional medication review processes often miss. Participants consistently reported increased confidence, awareness, and a desire to take greater agency in managing their health, and some even went on to run sessions independently.

To scale this work nationally, across England and potentially the devolved nations, Care City recommends a range of coordinated strategies that support both structured delivery and grassroots adoption:

1. Establish a Dedicated Hosting Organisation

Setting up a Community Interest Company (CIC) or similar non-profit structure to hold, protect, and develop the LTDAM resources would provide a formal base for future work. This organisation could:

- Act as a national custodian of the stories and facilitator guide.
- Offer light-touch coordination for those delivering sessions locally.
- Lead further development of the model (e.g., new stories, translated versions, simplified/plain English versions of stories, stories in additional languages, app development).
- Provide basic quality assurance and learning infrastructure (e.g., feedback channels, facilitator network). A simple digital feedback loop, collecting data from facilitators and participants via the website, could help track impact at scale, refine delivery, and support future funding bids. Light-touch analytics and storytelling-based feedback can continue to shape the approach while avoiding burdensome evaluation.
- Access external funding and income streams to ensure sustainability of LTDAM. This could include
 funding applications to national funders/charities as well as commercial models targeting health
 bodies (e.g. ICBs, PCNs, NHS trusts) looking to address polypharmacy locally. These commercial
 models could include the delivery of sessions through experienced and trained facilitators.

2. Maintain a Digital Hub for Open Access Delivery

Maintain the central LTDAM website to make the stories, facilitator guide, and delivery resources freely available to volunteers, community leaders, and professionals. This could include:

Downloadable and printable story packs and guides.



- A sign-up pathway for individuals interested in running their own sessions.
- A map or tracker of LTDAM sessions being delivered.
- Case studies and video testimonials to inspire confidence and uptake.

3. Launch a Volunteer Mobilisation Campaign

To grow delivery capacity organically, we recommend a targeted social media and awareness campaign aimed at:

- Retired health professionals.
- Local community connectors.
- Faith-based leaders and volunteers.
- Carers and peer supporters.

This campaign could promote the stories as a "ready-to-go" tool for meaningful engagement and encourage volunteers to run sessions independently, using a flexible model and supported by the website.

4. Integrate with Existing Health and Social Care Structures

Explore partnerships with:

- **Primary Care Networks (PCNs)** to embed story-led sessions as part of social prescribing or patient engagement efforts.
- Integrated Care Systems (ICSs) to align with wider polypharmacy reduction strategies.
- **Public Health Teams** and Healthy Ageing programmes to distribute materials and support local delivery.

This could include providing training or briefings for social prescribers and community link workers, who are well-placed to host or refer people into LTDAM sessions.

5. Invest in Digital Support Tools

To support facilitators and reduce dependency on formal training, develop a lightweight AI-powered chatbot or virtual co-facilitator, accessible via the LTDAM website. This could:

- Guide facilitators step-by-step through session planning.
- Offer real-time support for common questions.



- Provide prompts and reflective questions for different stories based on group characteristics/experiences.
- Suggest adaptations based on group type or setting.

This would particularly help lone facilitators or those working in low-resource settings.

6. Commission a Strategic Media Campaign

A mainstream media campaign, inspired by the success of segments such as Professor Green's piece on *The One Show*, could raise national awareness of the medication burden and the role of personal storytelling. This would:

- Help normalise conversations about polypharmacy.
- Encourage the public to reflect on their own regimens.
- Signpost viewers to the LTDAM website and local events.

Consider partnerships with NHS England, patient charities, Age UK, and national broadcasters to reach older audiences and their families.

7. Explore Accredited Training and CPD Pathways

As the model grows, develop optional accredited facilitator training (e.g., via CPD-certified modules or e-learning) to support more structured roll-out in clinical and community care settings. This could help build trust in the approach among clinicians and commissioners.

8. Develop a Mobile App to Expand Accessibility and Engagement

To complement the website (www.medicinestalk.co.uk), we recommend developing a dedicated Let's Talk Differently About Medicines app. This would enhance accessibility and create a more personalised, interactive experience — especially for those less comfortable navigating websites or who prefer mobile-first engagement.

An app would offer several advantages over a traditional website, including:

- **Ease of Access**: Once downloaded, an app is easier to return to and requires fewer steps than accessing a website via a browser especially important for older users or those with lower digital confidence.
- **Offline Functionality**: Stories, facilitation tips, and reflective tools could be accessed offline, removing barriers for users without reliable internet access.



- **Push Notifications**: The app could prompt facilitators or participants to follow up on conversations, revisit stories, or access new materials, helping to maintain momentum and reflection.
- **Customisable Experience**: The app could learn from user interactions to recommend stories or discussion prompts tailored to interests, conditions, or group types.

The app could also include a built-in AI powered chatbot as described above. The app could be piloted with early facilitators and co-designed with users from different backgrounds to ensure accessibility and relevance.

Discussion

This evaluation set out not only to test the impact of the *Let's Talk Differently About Medicines* (LTDAM) stories, but also to develop a robust, user-informed facilitator guide to support their delivery. Across 14 facilitated sessions and follow-up conversations, participants described a wide range of personal, social, and practical impacts, from feeling more confident to speak with GPs to initiating conversations about reducing or stopping medicines altogether. These outcomes provide tangible support for the issues highlighted in the literature and policy landscape that originally informed LTDAM's development.

The emotional resonance and relatability of the stories gave participants permission to voice experiences and concerns that are often marginalised in traditional healthcare settings. This aligns closely with evidence from the APOLLO-MM study, which found that medication reviews are often rushed, unclear, and disconnected from the day-to-day realities of living with multiple medicines[1,2]. Similarly, our sessions frequently revealed systemic gaps: participants reported feeling disempowered, uncertain about the purpose of their medications, and hesitant to challenge prescriptions, especially in the absence of consistent GP relationships.

While Structured Medication Reviews (SMRs) are promoted as a key intervention to address polypharmacy, there is growing recognition in the evidence base that their effectiveness remains limited without genuine person-centred dialogue[3,4,5]. Recent studies point to the need for approaches that go beyond clinical checklists — ones that meaningfully engage people in conversations about what matters to them[6,7]. LTDAM offers one such approach.

This evaluation demonstrates that storytelling, particularly when facilitated in a supportive, community-based setting, can unlock deeper, more reflective conversations about medicines. The stories gave participants a way to explore emotions like frustration, fear, and uncertainty, and to connect these feelings with questions of autonomy, burden, and care. Many described the sessions as the first time they'd felt safe to express doubts about their medications or consider alternatives. In several cases, these reflections translated into real-world actions: requesting reviews, reducing or stopping medication, challenging prescribing processes, and encouraging peers to do the same.

Importantly, the co-design process used to develop the delivery model and facilitator guide was instrumental in achieving this. Working iteratively with people with lived experience helped ensure that sessions were culturally appropriate, emotionally safe, and practically grounded. The facilitator guide, refined through 14 sessions and informed by real-time feedback, provides a flexible and inclusive framework for delivery.

A key recommendation is that the stories and facilitator guide continue to be made freely available online. This opens up the possibility for wide-scale, grassroots delivery of LTDAM sessions by community leaders, volunteers, carers, or retired professionals. The availability of these resources would empower others to pick up and deliver LTDAM without the need for formal training or institutional backing; this is a highly scalable model that retains its community roots.

To fully realise this potential, a range of additional enablers are recommended. These include the establishment of a dedicated hosting organisation to maintain the resources and support quality assurance;



the creation of a digital hub with downloadable materials, delivery guides, and facilitator support; and a national awareness campaign to promote uptake. Further innovations, such as a virtual AI co-facilitator to support independent delivery, or integration with social prescribing pathways could extend reach and impact, particularly in underserved areas.

However, the stories alone cannot overcome structural barriers in the health system. As participants noted, follow-up actions often require support: time with a GP, access to safe deprescribing advice, or simply clearer guidance about who is responsible for reviewing medicines. Some participants expressed frustration that attempts to raise medication concerns were dismissed or met with warnings rather than collaboration. These challenges highlight the need for parallel system-level changes, ensuring that the momentum sparked by LTDAM is met with responsive and person-centred clinical practice.

In summary, the LTDAM stories represent a simple but powerful intervention: one that brings humanity, reflection, and agency back into conversations about medicines. Their successful delivery and documented impact suggest a clear opportunity for wider adoption, both as a community engagement tool and as a supplement to formal medication review practices. With a facilitator guide now available, the foundations for national scaling are in place. What remains is to invest in the infrastructure, partnerships, and outreach needed to realise that potential.

Conclusion

This project set out to explore whether storytelling could provide a new way to spark meaningful conversations about polypharmacy, and whether those conversations could, in turn, support people to feel more confident, informed, and in control of their medicines.

This evaluation demonstrates that the approach works. The stories resonated strongly with participants, prompting personal reflections and immediate dialogue in the room, and inspiring longer-term conversations and actions beyond it. For many, this was the first time they had spoken openly about the emotional and practical burden of managing multiple medicines.

Alongside this, the project enabled the development of a facilitator guide, refined through real-world testing and co-design. It provides a flexible, practical tool that enables others to deliver story-based sessions with confidence, care, and contextual sensitivity. The guide and stories will be made freely available online, offering an open invitation for community groups, volunteers, and professionals to pick up and use the resources in ways that work for them.

Participants' reflections also revealed significant systemic challenges, from inconsistent access to medication reviews to cultural reluctance to challenge medical authority. While LTDAM cannot address these barriers alone, it offers a vital bridge: a low-cost, high-impact method to bring the human experience of medicines back into focus.

The evidence from this project points to real potential for wider adoption. With national coordination, digital infrastructure, and volunteer mobilisation, LTDAM could be scaled across the UK, enriching the way we talk about medicines and helping to shift the culture of prescribing and reviewing towards one that centres people, their values, and their lived experience.

This is not a clinical tool, nor is it an educational campaign. It is something quieter, but just as powerful: a way of making space for people to be heard, and for conversations that matter to begin.

Appendix A: Evaluation Core Questions

The following questions were asked of all participants engaging in session follow ups. They were adapted as necessary to suit the setting and audience, while retaining their essential focus.

In larger groups, some of the questions were translated into a series of answer statements on small cards (see below). These were handed out to participants, who were asked to choose from them, selecting those statements they felt captured noticeable impacts upon their thoughts, feelings and practices around medicines since reading the LTDAM stories. Participants were then asked to share with the group why they had chosen the specific statement. Note: all these answer statements on cards were framed as to read "Since reading or discussing the story...."

Return to Evaluation Design and Methodology

- Looking back on the session now, what stands out most vividly for you? Why do you think that was?
- What was your biggest takeaway from the session? Why is that?
- Would you say that your confidence around medicines has changed at all since the session? Why? How did the session impact that?

Answer statement on card: My confidence around medicines has changed

• In what ways (if any) did the session impact how you've been thinking or feeling about medicines recently? Why is this? This can be for good and bad.

Answer statement on card: I've been thinking or feeling differently about medicines.

• Have you made any changes to your medicines or how you manage them, or taken steps to do so, since the session? Which changes? Why is that? Do you feel the session impacted this?

Answer statement on card: I've changed my behaviours around medicines

• Since the session are you having any more or different conversations about medicines? Why is that? Do you feel those have been influenced by the session? With either (1) People you joined the session with? (2) friends and family?

Answer statement on card: I'm having more or different conversations around medicines with friends and family



• Do you feel the session influenced the kind of conversations you're having with healthcare professionals (e.g. GPs & Pharmacists) around medicines? In what ways? Why is that?

Answer statement on card: I'm having more or different conversations around medicines with healthcare professionals (e.g. GPs and pharmacists)

• Did the session impact how confident you feel in talking to healthcare professionals about your medicines? Why is that?

Answer statement on card: My confidence in talking to healthcare professionals about medicines has changed

- Did the session give you space to talk or think about anything you'd had on your mind, but hadn't had the opportunity to before? What helped you be able to do that?
- Since the session, do you feel you better or worse understand why you're taking the medications you are? Why is that?

Answer statement on card: I better/worse understand why I'm taking my medications

• Did the session impact how able you feel to have conversations that support your priorities around your health and your life, since the session? Which priorities?

Answer statement on card: I feel better able to have conversations that support my priorities around my health and my life

• Did the session make you think about how we might work together better as a community to help people manage or reduce their medications?

In what ways? Where did this idea come from?

Answer statement on card: I've had ideas about how we might better work together as a community to help people manage or reduce their medications



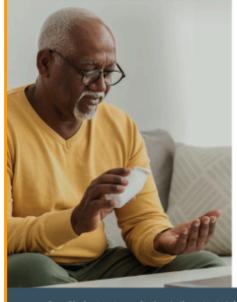
Appendix B: First Iteration of Recruitment Leaflet

Let's talk differently about medicines

Are you based in North East London?

Are you over 65?

Do you take more than 5 different medicines, or care for someone who does?



Older people often need to take many medicines, which can increase problems like falls, hospital visits, and side effects. Managing multiple medications can be challenging, but with the right support can help improve your health and wellbeing.

We want to help you have better conversations with healthcare professionals about your medicines and regularly review what's right for you.

Let's talk differently about medicines is a collection of stories about people like you who take many medications. We want to learn how these stories can help you have better conversations with your GP about the medicines you take.

If you're interested in joining a storytelling workshop and sharing your feedback on these stories, please visit www.carecity.org/lets-talk-about-meds, scan the QR code, email theteam@carecity.org, or call 0208 064 1996.



Care City is a local organisation dedicated to helping people in North East London live happier, healthier lives. We work with residents and healthcare partners to improve services and make our community a better place to grow old.

carecity.org

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Appendix C: Final Iteration of

Recruitment Leaflet

Let's talk differently about medicines

Are you based in North East London?

Are you over 65?

Are you prescribed medicines or care for someone who does?



As people age, they can be prescribed more and more medicines. If this sounds like you, you are not alone. Many others feel the same way. It's not something we often talk about, is it?

We want everyone to have better conversations with healthcare professionals about medicines and regularly review what medicines are right for us.

We are inviting you to a free workshop to look at what others have done and hear about your situation.

Please visit
www.carecity.org/participate,
scan the QR code,
email theteam@carecity.org,
or call 0208 064 1996.



Care City is a local organisation dedicated to helping people in North East London live happier, healthier lives. We work with residents and healthcare partners to improve services and make our community a better place to grow old.

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Background

Background to the LTDAM stories

The LTDAM stories were co-authored by Professor Deborah Swinglehurst and Dr Nina Fudge, based on research conducted between 2016 and 2021 at Queen Mary University of London (QMUL).

In the APOLLO-MM project (Addressing the Polypharmacy Challenge in Older People with Multimorbidity) 24 people were studied for up to two years. They were aged 65 or older and had been prescribed ten or more different items of regular medication. The research team interviewed these people, visited them regularly at home, and went with them to medical appointments. The team also filmed some of their consultations with their doctors. In addition, many hours were spent observing and talking with health professionals in three general practices and four community pharmacies.

As part of this project, the team worked closely with Dr Alison Thomson (QMUL) and members of PenPEG (Peninsula Public Engagement Group) to build this collection of stories. The characters, names and stories are fictional but are inspired by encounters with research participants and the findings from the APOLLO-MM study.

The research team wishes to thank the patients and staff who took part in the development of the stories, members of the Expert Advisory Group, the patient panel and public engagement panel who gave their time and expertise to make the research possible. Thanks also to QMUL's Royal Literary Fund Fellow, Elizabeth Cook, and members of the APOLLO social science research group who commented on earlier drafts of the stories.

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Disclaimer

If you are concerned about your medicines or if any of the stories in this collection raise issues that you would like to discuss further, please contact your doctor or pharmacist. Please do not make changes to prescribed medication without consulting with a health professional.

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