MEMORABLE: MEdication Management in Older people: Realist Approaches Based on Literature and Evaluation

Stakeholder Group Meeting 1: Minutes

Teleconference: Tuesday 30th January 2018, 1.00-2.00pm

Aston: MB437

Chair: Anne Watson, Chief Investigator: Ian Maidment

In person: Cyril Cooper, Sandeep Pahal

On phone: Lesley Hodgson, Hadar Zaman, Lelly Oboh, Peter Crome, Carmel Darcy, Sally Lawson, Naveed Iqbal, Hemant Patel.

Apologies: David Harris, Stuart Hutchinson, Sheila Hardy, David Shukla, Liz Bates, Nark Porcheret.

Minutes

1/2. Welcome and introductions

3. MEMORABLE – overview and questions

PC – How many interventions do you think will emerge from this research, 1 or multiple?

IM – multifaceted intervention applied flexibly most likely to be successful.

HP – How will you define the success of the intervention? What is the key outcome for it?

CC – Outcome of QOL good. Important to establish what is currently going wrong.

IM – likely to number of possible outcomes (QoL, process e.g. STOPP/START, clinical, cost).

LO – Technical solution is unlikely. Keeping an open mind to possible solution at this point is correct.

NI – How will the output/intervention be tested?

SP – Pragmatic approach endorsed – possibly looking at care home admission/re-admission.

LH – The issue under study is one of many factors influencing some hospital and care home admissions

4. Realist Methodology – overview and questions

SL presented.

5. Discussion topic: candidate programme theories about how medication management might currently work (if, then statements)

HP – Program theories 1 and 2 OK, 3 suggests practitioners fixed and not flexible in their approach and he felt that was not the case.

LO – Citing adherence as an example, do people find out what the patient wants? Stated she was able to be flexible in her role but that is not the case for all practitioners. Also importance of organisational structures.

HZ – Differing prescribing practices /roles of DR, nurse and pharmacist need to be taken into account in the statements and intervention(s).

CC – Stated his long-term conditions were now well controlled and he was able to manage a complex med regimen. He had a poor QOL when he had a period of years on long-term oral steroids which when he switched care he felt had been a poor and incorrect prescribing decision. He wished to make the point the wrong prescribing can be the root of many issues.

LH – Made the point about differing rules set by different care agencies led to inconsistency in meds administration practices. The example of some agencies not allowing staff to apply steroid creams was given. Insulin also an issue. Lack of standardisation in role and scope of role of formal carers.

She also highlighted the issue of patients being discharged home from hospital having been deskilled relating to administering their own meds and understanding them whilst in hospital creating issues on discharge. She made the point that informal carers tend to take on all and any aspects of meds man beyond the boundaries that formal carers are given.

SP – agreed with comments from LH.

HZ – Indicated that training packages for training care workers was on the national agenda and importance of competency of carers.

CD – programme theory for practitioners was further developed than PrT for patients and carers.

SL – outlined that this was a reflection of the status in the literature that there was more info in the practitioner area than for carers and older people. Little on QoL and emphasis on adherence.

SL – do we need to distinguish between prescribing and delivery?

IM - maybe will be captured through the interviews

CD – Point of prescribing is a problem.

HZ – prescribing easier than de-prescribing; important set criteria for success and stopping the medication when it is started.

SP – from commissioners perspective quantitative data will be needed demonstrating benefits.

6. Any other business (ALL)

Agreed post vouchers for all contributions at end of project.

7. Date and time of next meeting: April 2018

IM to send a doodle poll

Item 3: MEMORABLE – overview

Background

The number of older people is increasing rapidly. Half of people aged 75 or more live with two or more long-term conditions. Safe and effective use of medication to manage such long-term conditions is a key challenge for health and social care services. Medicines used for one long-term illness can worsen another illness and cause harm. People with a number of illnesses may take many medicines and thus

remembering to take the medicines may be difficult. Medication errors may also be more common, when people take many medicines.

Doctors, nurses and pharmacists all may support older people with their medication. Some older people will manage their medications on their own, others will have help from both informal (family/friend) and formal (paid) carers. The level of support an older person gets from all those involved varies and this support needs to be co-ordinated. The consequences of getting things wrong are stark. In the UK every year, medication related adverse events have been estimated to be responsible for 5,700 deaths, 5 to 8% of unplanned hospital admissions, and cost the NHS £750 million. If we can improve the use of medication in older people with multiple long-term conditions this will reduce avoidable harm and improve quality of life.

Aim

MEMORABLE, which is funded by the NIHR (the National Institute for Health Research; the research arm of the NHS) aims to develop outline way(s) ('intervention[s]') of supporting older people living in the community and their carers to safely manage their medication.

It is collaboration led by Aston University and also involving the Universities of Oxford, Sheffield and Wollongong (Australia), and Birmingham Community NHS Trust.

Design and Methods Used

We will learn lessons from the literature and from interviews with people with experience and knowledge.

1. Literature Review

We will be using a particular method of literature review ("realist synthesis") that is ideally suited for making sense of complex processes. Documents containing information on supporting older people in the community to manage their medication will be brought together to identify 'what works for whom, in what circumstances, how and why?' The review will enable us to build an overall understanding of why processes are more or less successful and under which situations.

2. Interviews

The interviews will build on and expand the literature review; if the interviews identify new areas we will go back and review the literature in that area. Older people, including carers, and clinicians will be asked what helps them, or the people they care for manage their medication.

Finally, we will combine information from the research literature with information from the interviews to develop a proposed approach for supporting older people living in the community in managing their medication. We will seek further funding to finalise our approach and test whether it is helpful in a clinical trial.

The project will be supported by a key "Stakeholder Group" – this group - containing clinical staff, patients and carers. Members of the group will advise us whether our approach makes sense and is likely to work in practice.

For more information on MEMORABLE check the project web-site www.aston.ac.uk/memorable

Item 4: Realist Methodology – overview

Introduction

Realist research is a relatively new methodology. Realist researchers are interested in understanding how interventions work in the real, complex world we live in. For them, it is people, individually and together, who make interventions work or not. How people do this can't always be measured but can be understood by exploring the pattern of circumstances, decisions and actions that together lead to outcomes. Thus, realist researchers are concerned with complexity (people in a social world) and causality (how people respond to and bring about change). The more researchers know and share about how interventions work, the more evidence will be available to improve intervention design and the likelihood that preferred outcomes will be achieved.

How do realist researchers think about interventions?

An intervention is something that is done to bring about change e.g. a policy or programme. Medication management is an intervention to improve the use of medication and people's outcomes through specific practitioner activities such as prescribing, reviewing or de-prescribing and what older people and carers do such as getting, continuing to take or stopping medication.

Realist researchers want to uncover and understand the theories, evidence and experiences to explain how interventions might work in the real world. They do this by looking at established theories that can inform understanding at a general level such as theories of behaviour or change. They also develop what they call "programme theories", specific to the intervention they are researching. These are written as 'if then' statements e.g. if people do 'a' because of 'b', or if process 'c' generally happens, then 'x' might result. A relevant example for medication management might be: if someone has an in-depth consultation with a healthcare practitioner who is knowledgeable, skilled and trusted so they can share the decisions about taking medications, then they are more likely to take their medications, feel better and be able to do more of what matters to them.

Once these programme theories are set out, realist researchers gather and analyse evidence. In MEMORABLE, this is being done by exploring specialist literature and interviewing people to hear about their experiences. From this analysis, the researchers then revise and finalise the programme theories.

Of all the possible circumstances, decisions and actions that together lead to the outcomes associated with an intervention, realist researchers are concerned with those that are most likely to achieve the outcomes that matter to the people involved, as well as identifying which circumstances, decisions and actions they can influence to improve them. Also, by following a realist research process and developing programme theories using quantitative and qualitative data, recommendations such as a framework to improve practice and outcomes are evidence and experience based.

How is realist methodology being used in MEMORABLE?

The process being followed in MEMORABLE involves scoping the intervention > setting out **candidate programme theories*** > gathering evidence (literature) and experience (people's stories) to identify patterns of circumstances, decisions and actions that together lead to the outcomes, from which to revise programme theories > setting out **final programme theories*** > and from them, developing a **framework for medication management***.

Members of the Stakeholder Group are invited to share their experience and expertise as they comment on and contribute to those items marked with *****. These will be presented as a series of Discussion Topics over the course of five meetings (January, April, July, October and December 2018).

Item 5: Discussion topic: candidate programme theories about how medication management might currently work

These were developed by the Research Team (Andrew Booth, Geoff Wong, Ian Maidment and Sally Lawson) at a workshop on 5th January 2018. They are based on an initial analysis of 24 articles selected for their relevance to this topic and informed by the Team's specialist expertise and experience.

There is one candidate programme theory for each of the three interest groups in the research: older people, carers and practitioners (across health and care).

Discussion: based on your experience and expertise:

- Do any of these candidate programme theories fit (or not) with what you know or have experienced about how medication management works;
- Please explain or give examples to illustrate your opinion about this; and
- Any other comments.

1. Older people

If an older person, living in the community with multiple diagnoses and complex medication regimes, feels there is a dissonance / difference between their own priorities and those of the practitioners dealing with their medication management, **then** positive outcomes will not be achieved for and with them.

2. Carers

If an informal carer who is providing help with medication management for an older person living in the community with multiple diagnoses and complex medication regimes, feels there is a dissonance / difference between the priorities of the person they care for, themselves or the practitioner dealing with their medication management, **then** positive outcomes will not be achieved for and with the older person.

3. Practitioners

If a practitioner feels that they have to focus on structural / practice outcomes, **then** they are not able to accommodate other agendas / priorities, **leading to** a lack of influence on the knowledge, attitudes, behaviours and outcomes of older people who are living with multiple diagnoses and complex medication regimes in the community.

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Stakeholder Group Meeting 2 (deferred): Progress Summary

Chair: Anne Watson, Chief Investigator: Ian Maidment

Background

The MEMORABLE Stakeholder Group held its first meeting on 30th January 2018. The meeting received a briefing on MEMORABLE and on realist methodology. Members also discussed 3 candidate programme theories about how medication management might currently work (if, then statements). Minutes were circulated after the meeting.

Since then, considerable effort has gone into making progress with the research by continuing to review the literature (Work Package 1). However, the main priority has been to carry out interviews with older people, carers and practitioners (Work Package 2). This paper summarises progress.

Currently, there are no significant outputs for the Stakeholder Group to discuss.

Research Progress

Work Package 1: Literature review:

24 articles are being reviewed in more detail to map out the circumstances, decisions and actions that together lead to the outcomes associated with medication management. This is specific to older people, living at home, with several long term conditions and taking at least 5 medications each day or if less, taking a number of medications that are difficult to manage. Currently, the literature being analysed tends to focus on adherence as a process and as an outcome, sometimes with the addition of 'quality of life' as a catch-all for older people's perspective, with limited explanation of how adherence is achieved and sustained over time and at different stages, and as needs and concerns evolve. Data on older people's outcomes is poor and the Chief Investigator and Research Associate are currently discussing a concurrent, short study with a PhD student to explore this issue further.

Work Package 2: Interviews:

42 older people, carers and practitioners have been recruited to MEMORABLE (target up to 65 across all three groups) and 21 interviewed. The breakdown of interviews is as follows:

- older people: 10 interviewed of 12 recruited (target up to 20);
- carers: 6 interviewed of 11 recruited (target up to 25); and
- practitioners: 5 interviewed of 19 recruited (target up to 20).

Of these 21 interviews, 1 was completed in December and, after a lot of work on recruitment in January, 12 interviews were carried out in February and 8 in March. Recruitment continues to go well. The Research Associate's target is to complete around 10 interviews each month, typically carrying out 2 digitally recorded interviews a day.

The interview schedules for all groups enable the researcher to collect demographic information, develop a short pen portrait of each interviewee and then gather the detail of what they understand and experience in 'medication management'; information about who is involved, doing what, to make it work as a process, now and in the future; and the outcomes they want to achieve from taking

medication. Finally, if interviewees have not made reference to it, they are also asked about their views and experiences of whether a difference between their priorities and those of other people involved in their medication management affects their outcomes. This specifically addresses the relevant candidate programme theory although without using research terms. Interviewees are also encouraged to add any information that comes to mind as a result of taking part in the interview.

From the interviews, it appears that older people develop routines to manage their medications, many locating their pills to prompt them e.g. at their bedside for 'before breakfast' or 'before going to bed' or in the kitchen to reinforce the association with meals, whether in original packaging, clusters of foils or blister packs: '*I'm more ingenious than organised'.* Several use IT systems for appointments and repeat prescriptions. GP's are generally seen as key to medication management overall, although many older people identify a role for pharmacists at particular stages e.g. dispensing, information. For many older people, there appear to be distinct skills in managing their medication as well as navigating the system through which it is provided, particularly where it is fragmented: '*I know enough to work the system… but need to push'*. Co-ordination and consistency are valued. Family carers play a key role in supporting some older people where there are concerns about changes in capacity and risk. However, their situation appears more conflicted as they work to balance the interests of the person they care for, whether living in the same house or separately, and the requirements and changes instigated by practitioners: '*why mess with it'?* There is a clear 'carer burden' emerging in their stories: '*I have to take an awful lot of responsibility to make it work'*. Finally, there is limited data to report from practitioners; currently small numbers and limited roles. This is a diverse group and therefore the research priority is to contact the range of those engaged in medication management with older people living at home. In particular, this goes beyond the readily recognised roles of doctors, and the emerging contributions of pharmacists and specialist nurses, to include housing and social care staff, as well as formal carers (direct and independent providers). Recruitment through sites and personal and professional contacts is being targeted to ensure this coverage.

Next steps

The Research Associate will continue to analyse the 24 articles, working into the detail of what is written about how medication works (Work Package 1). Additional articles may need to be identified to address some of the gaps in explaining this process as well as to follow up particular topics of relevance e.g. shared decision making. At the same time, she will also continue to carry out interviews (Work Package 2) to get good coverage of the issues from different perspectives, until the end of May or early June. She will also begin to analyse the interview data and map it against the findings from the literature review. The Project Group will oversee this work.

In late June/early July, the Stakeholder Group will receive meet up and a summary report with initial findings from Work Packages 1 and 2 to consider.

If members have any questions about the work on MEMORABLE so far, please contact Ian Maidment (Chief Investigator: i.maidment@aston.ac.uk) or Sally Lawson (Research Associate: s.lawson2@aston.ac.uk).

SAL/19.03.18

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Stakeholder Group Meeting 2/3: Minutes

Notes from discussions (SAL): 28/29.06.18

Present: Meeting 1: Peter Crome, Sheila Hardy, Hemant Patel + Anne Watson; Meeting 2: Anne Birkett, Lesley Hodgson, Lelly Oboh: IM, SL at both meetings.

Item 3: MEMORABLE – progress with MEMORABLE.

- Progress acknowledged – emerging issues resonate with members' experiences;
- Emerging themes:
    - Importance of '**burden**' in all stages and how it is managed - increased, decreased: burden increases with polypharmacy – but an expectation that older people and carers will cope, despite risks. Also, practitioners see benefits of medication whereas older people and carers see the work – remembering to order, making the order, collecting the medication (pills, patches, drops and creams) – these may not run out at the same time. Also may have District Nurse for injections;
    - Policy changes may add to the burden particularly on GPs by creating more interfaces and complexity
    - MURs may also add to the burden on GPs as the community pharmacy send recommendations to GPs and do not institute the changes
    - Hierarchical and often paternalistic **relationships** within and between practitioner groups that can translate into 1:1 relationship with older person and carer;
- Key interventions at Stages 2 and 5: small elements in terms of timescales in the medication optimisation journey where 1:1 work (clinicians:patients/carers) happens e.g. patient information, shared decision making> informed decisions – getting consistency across practitioners;
- MEMORABLE2 proposal in preparation: Interventions proposed at the end of MEMORABLE should not add to work done by practitioners.

Item 4: MEMORABLE – discussion topics

1. **Medication management is not 'one thing':**
    - 5 stage process: validated;
    - Potential of Stage 5 'medication review' – medication management + relationship/communication;
    - Adherence (what people do) vs deprescribing (what practitioners do): reduce meds and simplify regime; there was agreement that deprescribing was easier to achieve if the medication was first introduced on the basis that it may later be ceased rather than being life long
    - Risk where prescriptions issued but medication not taken (non-adherence/patient led deprescribing) – leading to significant waste;
    - Importance of a adjusting regimes for best fit e.g. form and timing: **always simplify**;
    - Where is there accessible information about medication and medication management?: particular issue with insulin (e.g. new products). Where is there on-going support on an as-and-when basis?: community pharmacies. Is there consistent training for front line staff: variable?

2. **Older people's goals about what they want from their medication and how, is very important to them:**
    - Older people and carers focus on 'quality of life' outcomes: practitioners on e.g. guideline/outputs and policy delivery, cost effectiveness; One member of the stakeholder group commented that they felt practitioners also focussed on quality of life outcomes for patients as well as policy outputs and cost effectiveness.
    - Motivation important to managing medication and engaging with health and care system;
    - Older people often don't **discuss practicalities of taking medication when it's being prescribed** but practicalities may be the break-point in adherence. Nurses/community pharmacists can help with this and instil confidence that they can cope;
    - Some older people need 'prescriptive' support to self-manage so they are motivated to deal with their own complexity, including any medication change and the knock-on effects;
    - Some outcomes not measurable e.g. 40 year benefit – more often measured in the short term as e.g. adherence, and overall management measures e.g. lipid levels, BP reduction;
    - Some older people 'on the cusp' of coping – but may be signs e.g. hoarding than taking or not managing changes;
    - Some older people who are independent in medication management lose this and need help on discharge from an acute admission e.g. from District Nurse. **Largely cognitive reasons – competence / confidence.** The aim is for them to be independent again but perhaps only 50% achieve this. Some older people accessing Intermediate Care and getting rehab for this between acute and home;
    - Importance of simplifying regimes – taking time, explaining, repeating, providing reassurance – individualised – explaining pro's and con's / ways of minimising risk.
3. **Family carers can feel they are carrying a lot of responsibility when they support older relatives with their medication:**
    - Gradual transition from an older person managing their medications independently to needing help from a family carer (need to balance role as carer with relationship). Ambiguity of their informal carer role and therefore their relationship with practitioners (if not Power of Attorney);
    - Important role;
    - Issues for carers about how much support and information they receive, information flows and how they fit their increasing role with the rest of their life;
    - Carer 'training' (very little training for informal carers; many different informal carers may be involved leading to consistency issues);
    - Concerns raised for older people who do not have a carer to advocate for them or to support them;
    - From MEDREV: carers often want someone to talk to.
    - Community Pharmacy could act as a key role in signposting/advocacy. Help to reduce some of the burden. Often identify when things appear to be going wrong (when someone about to be admitted to hospital), but that doesn't appear to be communicated.
4. **More and more practitioners, in different roles, from different organisations and with different ways of working are involved in medication management:**
    - ***'You are at the mercy of people who care for you'*:** concerns for older people without family.
    - Blurring boundaries as roles develop but services, practice and relationships still in silos – need to changed and clarified for communication: sharing and transfer of information etc.

- **Multiple boundaries in local areas (different people to liaise with, different ways of working, different relationships, different communication systems)** – a district nurse may work into e.g. 7 GP practices – multiple links between pharmacies and several GP practices – GP's may have several pharmacies to liaise with – complexity;
- Some pharmacists/nurses stated they would potentially change a script without necessarily discussing with GP. Other stated that they would always discuss with GP before making changes. All confirmed the importance of trust and relationships.
- ***'Older people and carers need one person to go to'*** – for information, advocacy and co-ordination – and who will take that responsibility on;
- ***'Practitioners need to negotiate and influence while keeping the patient in the middle'***: practitioners need to develop these skills and use them in the patient's interest: takes time and effort;
- GP as gatekeeper in the community: collaborative focus: supported by nurses and pharmacists over sustaining day-to-day routine;
- GP's willingness to change medications prescribed by consultants varies;
- Increasing role of pharmacists over last few years, including within GP practices, as well as nurses in specialist roles linked to the day-to-day management of long term conditions; Questions asked about whether GPs accept other prescribing. Group members confirmed this to be the case provided boundaries of prescribing set up in the first place. Consultant pharmacist stated 97% of their recommendations implemented.
- District Nurses and specialist nurse role and practice inconsistencies;
- District Nurses may spend about 40% of their day on medication management – including up to 4 visits daily, including checking prn meds even if declined – key boxes for access make this easier / quicker; social services would generally automatically refer someone with just medication issues to primary care;
- District nurses have 'networking events' regularly: a place to link with colleagues, learn about new services and roles locally;
- In secondary care, prescriptions signed off by more junior staff – may be for treatment associated with admission rather than as a result of review within longer term condition(s) management;
- Care Act determines roles in assessing and providing for care needs – social care may not be provided where needs are for medication support only and may look to family for this – but social workers can refer for medication review for regime to be simplified;
- Rules between health and care need to enable them to work as partners and complement what they do. A lack of joint working reduces capacity, increases waste. Need to go beyond roles of doctor, nurse and pharmacists e.g. therapists, social workers and formal carers – working 1:1 with older people and family / relatives. The model of unified health and care offers potential.

SAL/02.07.18, amended IM

MEMORABLE: MEdication Management in Older people: Realist Approaches Based on Literature and Evaluation

Stakeholder Group Meetings 4/5: Minutes

Chair: Anne Watson **Chief Investigator: Ian Maidment**

1. Welcome and introductions (AW)
2. Taking part in the teleconference (IM)
3. MEMORABLE – progress: notes attached (IM)
4. MEMORABLE – discussion topics: notes attached (AW and IM)
5. MEMORABLE – next steps: verbal report (IM)
6. Any other business (ALL)
7. Appreciation of participation (IM)

Present both dates: Sally Lawson (SAL), Anne Watson (AW), Ian Maidment (IM), Medha Kothari (MK)

4th Dec: Anne Birkett (AB) – carer for husband and mother, Alison Hemsworth (AH) – NHS England pharmacy technician, Cyril Cooper (CC) – layman and consumer of polypharmacy, Carmel Darcy (CD) – consultant pharmacist for older people – Northern Ireland, Sylvia Bailey (SB)– PPI on MEMORABLE, NHS England medicines safety board, Peter Crome (PC) – Consultant Geriatrician/Academic.

5th Dec: Lelly Oboh (LO) – consultant pharmacist for older people; Jaspal Johal (JJ) Dudley CCG Pharmacist.

Apologies: Naveed Iqbal, Geoffrey Wong, Sheila Handy, Judy Mullan, Sandeep Pahal, Judy Mullan.

Item 3: MEMORABLE – progress

MEMORABLE began on 1st May 2017 and runs until 31st December 2018. This 20 month research project is now moving towards completion. The results will then be submitted in a report to the National Institute for Health Research (NIHR, the research arm of the NHS who funded this study). The current situation is as follows:

a. **Work Package 1:** (review of evidence): the review of the literature is being written up. Mapped medication management as a five stage process. Reviewing stage 5 as believe it's a key stage for people with long term medication. We are focusing on Stage 5: Reviewing / reconciling medication linked to Stage 4: Continuing to take medication, as they appear to be key stages in

understanding how medication management works for older people living with long-term conditions who are taking multiple medications. Within this focus, we are exploring the central concept of 'burden': the work people have to do and their capacity to do it.

LO: how many older people and practitioners?

SAL: 12 older people, 19 practitioners – consultants, pharmacists, GPs, pharmacy techs, care managers and assessors, (Extracare model), nurses including community matrons, specialist nurses, front line care staff (administering or providing medicines) - 16/17 carers

LO: acknowledged rich dataset.

b. Work Package 2: (evaluation of experience): 50 interviews have been completed and their analysis is continuing.

c. Work Package 3: (synthesis): progress is being made with combined analysis of data from a. and b. We are writing and revising short statements that explain how medication management works e.g. 'Regular medication reviews and transition reconciliations by experienced practitioners, optimises medication management, by minimising the risk of treatment related problems'. Also 'When patients are informed about their illnesses and medications, they are less likely to experience negative emotions such as worry or distress, because they feel more in control'. These apparently simple but powerful statements are being revised as we use more data to 'trial' them. We are starting to use these statements as the basis for MEMORABLE's proposed interventions (see Item 4).

IM: combining work package 1 and 2 to give short statements then will trial/challenge the data against interviews and literature.

AH: who are the statements aimed at?

SL: language internal to project and attached to those statements will be interview data and literature, therefore can prove or disprove them to understand how medication management works, or not.

SB: mentioned the need for medication reviews to be conducted by 'experienced practitioners' who know the patient and work with the GP.

AH: all groups bound by profession codes. IM: acknowledged issue of fragmented care (found in project). Problem of communication. Information sharing is a priority to NHS. SL: emphasized the importance of continuity of care.

LO: how many of these statements are you writing? SL: 24 statements so far, with 11 from older people's interviews. SL: Interesting to see how people actively change their routines in order to stay in control. LO: yes, they do adapt and make those changes regularly. We see it in practice all the time.

LO: discussed the importance of control; people make adjustments to their medication regimens all the time. Some will be positive and some we may perceive as negative.

JJ: as healthcare professionals, we have a duty to encourage self-management of medications in patients. Take control of their medications as much as possible. High risk meds get priority for medication review including de-prescribing if possible. If receive requests from GPs/pharmacists for compliance packs, undertake review with the patient, and encourage them to keep control and maintain independence rather than going to the blister pack right away, especially if their regime is quite simple. Also actively encourage people to fill their own dosette boxes.

LO: ideally, we need to have face-to-face interventions to really understand each patient and make the proper recommendations for each individual and their circumstance. At least a conversation with your patients to understand their routines. Need to support and respect patient's decisions, and ask questions in non-judgemental way; listening skills are important. Sometimes we need to understand why the patient does things a certain way e.g. why do they space out their medications in a certain way. Need coaching type/real conversations instead of 'surface/transactional' conversations.

SL: avoid institutionalisation in the patient's own home.

IM: intentional and non-intentional adherence overlap; if you are less bothered about a medication, or think that it doesn't work, then you are more likely to forget about it.

Item 4: MEMORABLE – discussion topics

Examples of what we have produced:

a. we have generated a comprehensive, evidence-based Analysis Framework from the literature to structure the data and make it easier for us to see how medication management might work;
b. combining a review of the literature and an evaluation of what people experience has brought people's voices to the fore, highlighting how medication management works in people's day to day lives, strengthening our analysis; and
c. this combined approach has provided us with an evidence and experience base for our intervention proposals.

Intervention proposals:

d. **identifying and targeting individuals at risk from the burden of managing their medications:** by developing two 'Whooley'-type questions (https://whooleyquestions.ucsf.edu/), one about what people have to do to manage their medications and one about their capacity to

do those things. Getting 'yes' answers to both would identify people who need greater support to cope; and

IM: aims to develop an intervention that is simple to implement and doesn't add to burden. Identified need for "triage system"; need to identify individuals at risk of burden of meds, ask the two questions, and that's a trigger for some type of medication review. Questions can be asked by anyone and for example incorporated into MURs. Next grant (MEMORABLE 2): frame the questions. Issues with RCT – not generalisable in the real world.

PC: interesting and good idea, simple. Agrees RCT not helpful; would like to see the final questions.

SL: focussed around burden, two elements are 'workload' involved and people's 'capacity' to do the workload, 'What kind of things are you having to do and are you coping?'

AM: likes the principal; fits into all systems of healthcare and how we deliver healthcare now and how we might deliver healthcare in the future.

AB: indicated from a carer perspective she liked the idea of something simple. In her experience there is a big assumption that carers are coping. She has experience and skill and is coping but finding it difficult, but others may do not have the same experience and skill and are less likely to be coping. She emphasized that she like the concept as long as it remained simple.

CD: fantastic idea and simplicity is appreciated and managing burden. Preferred the word coping to capacity.

IM: need to link with policy e.g. NICE guidance.

CD/PC: agreed important, but the process by which NICE goes from the whole body of research to the key papers is unclear. NICE tend to focus on RCTs.

AH: might be able to offer further advice with linking to policy in due course.

CC: agreed makes sense, but acknowledged distance from research. IM: stated not expecting members of stakeholder to immerse themselves in the data (just the summary). SL: emphasised the value of Stakeholder Group feedback on the proposed interventions based on their individual experience and expertise.

IM: two questions that can be asked by anyone (any practitioner), which identifies if a more detailed review is needed or not.

JJ: have a similar triage approach using practice based pharmacists, but based on the number of medicines a patient is on in each subgroup of the BNF. Reviews can be note-based, over the phone or face-to-face particularly if very complex regimen. No formal protocol.

IM: yes triage tends to be based on complexity, number of medicines the person is on.

LO: The difficulty is knowing how people manage their medications. Patients are not thinking clinically, they are thinking about the burden and capacity of managing the medicines. A basic set of questions (four; these include how do you get your medicines and how do you use your medicines, whether they think their medicines are giving benefits or causing problems) are asked when we assess patients the first time. We need to use the whole workforce including non-pharmacists, community pharmacists to be trained on how to identify people that need a review/help coping. But we need to address and consider functional issues.

IM: yes these questions could be incorporated into MURs.

LO indicated she felt that a targeted approach to the type of resource deployed depending on the problem was needed. She illustrated that they had various staff functions from specialist pharmacists through to rehab support workers (RSW), each being deployed depending on the nature of the issues to be tackled.

SL asked if LO could provide a short summary that she could add to her vignettes that illustrate when integrated services are working well. LO and SL will link up following the meeting.

e. developing ways of providing older people and caregivers at risk with their own **individualised information** that they can use and share, tailored to their particular needs and experiences of living with several long-term conditions and taking many medications.

IM: information will focus on how the meds affect their daily life style? E.g. if someone is on insulin TDS, they can't go out on day trip in care homes because it can't be administered on the day trip.

SL: People say, 'I can get information on each diagnosis separately but not information for all the diagnoses combined.' Also, medication information specific to each drug. How can we most personalise information that reflects the complexity experienced by patients and carers?

AH: Individualised info – who will provide it? IM: non-specific, could be anyone.

SL: all getting different information from specialists, GP, pharmacist etc. and sometimes it's not practical because it's not one set of personalised information. Information package by co-production within MEMORABLE2. Co-production endorsed by SB.

AH: expressed some concern that this individualised material may put additional burden on professionals and asked if a template was anticipated.

IM: again probably part of next project, and confirmed aware needs to be simple and does not aim to add additional professional burden. SL: needs to emerge from better understanding of what is most

useful to patients and carers than what practitioners generally provide based on professional knowledge. What information they found useful and in what format?

AH: challenging concept, can see the importance but it's difficult to see a solution. Care navigation program would be useful to look into.

AB: agreed good idea, but could be a challenge. Social media could be used potentially; often assume older people can't use social media but many actually can.

LO: identified it rightly, the patient must be allowed to control their record as well. Mentioned My Medicines passport. Clinicians tend to be concerned with the accuracy of patient written information (they need to be more open minded).

JJ: medication review and de-prescribing information is available on the Dudley NHS formulary website

Agreed to hold final Stakeholder Group meeting – in March 2019 after final report submitted.

NB: subsequent to the meeting identified the area as an NHS priority: https://www.gov.uk/government/news/matt-hancock-orders-review-into-over-prescribing-in-the-nhs