# Addressing Medication Management for Older People with Multimorbidities: A Multi-Stakeholder Approach

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#### **ABSTRACT**

Multimorbidity, the presence of two or more chronic conditions, places a significant burden on health systems globally. People managing multiple chronic conditions face burdensome and complex treatment plans. Polypharmacy, the prescription of several drugs, is typical in this cohort, adding to the treatment burden and potentially resulting in dangerous drug interactions. The goal of our work is to design a medication management application for older people with multimorbidity, and those within their care ecosystem. In this paper we present findings from interviews and focus groups with 124 participants, including older adults, informal and formal carers, and healthcare professionals. We outline six design requirements and describe how our design process is grounded in a strong, theoretical behaviour change approach that will allow us to fully evaluate the effectiveness of our design for medication management for those with multimorbidity, supported by their care network.

# **Author Keywords**

Multimorbidity; Medication Management; Behaviour change; Multi-stakeholder; ICT.

#### **ACM Classification Keywords**

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous;

#### INTRODUCTION

There are strong concerns worldwide about the sustainability of health services due to the increase in healthcare expenditure, as well as disparities in the number of practicing healthcare professionals (HCPs). In the US, more than 60% of health care spending is on people with multiple chronic conditions  $^1$ . Within the EU, 70-80% of healthcare costs are spent on chronic diseases, corresponding to  $\epsilon 700$  billion per annum, while an

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estimated 50 million people in the EU live with multiple chronic diseases [15]. Nonetheless, health systems across the EU continue to focus on supporting a single disease framework of care. A primary challenge is, therefore, to create a patient-centric integrated care ecosystem to understand and manage multimorbidity (defined as the presence of two or more disorders and associated comorbidities) [15]. For people with multimorbidity (PwMs), services are often repetitive (multiple appointments), inconvenient, inefficient (patients may see different HCPs who give conflicting advice), burdensome and potentially unsafe due to poorly integrated and coordinated care [19]. This significantly reduces quality of life (QoL).

Polypharmacy, defined broadly as the chronic prescription of several drugs, is typical for PwMs [11]. This can often result in potentially dangerous drug-drug interactions [11]. The overwhelming pharmaceutical treatment burden on PwMs can be difficult to manage [7], [9]. Medication non-adherence is a significant problem worldwide with an estimated 50% of medications for chronic diseases not taken as prescribed [21], impacting recurrent hospitalization and survival rates [4].

Technology offers potential support in the self-management of medications for PwMs. A number of mobile applications for medication management are already available in the marketplace. These can be largely grouped into those providing information and those aimed at supporting adherence. In a comparison study of medication management applications, Grindrod et al. [6] found that although most medications are prescribed to those over age 50, mobile health applications failed to consider the needs and challenges for this age profile of users. In particular, existing applications fail to recognize the complexity of factors influencing non-adherence, especially for PwMs.

Research has identified that specific challenges experienced by PwMs and their carers include lack of adequate and plain language information, poorly coordinated services between HCPs and poor relationships/communication between HCPS, PwMs and carers [4], [6], [16]. There has been little examination, however, of what is needed from technologies to support multi-stakeholder collaboration in

<sup>1</sup> http://www.oecd.org/health/health-systems/48245231.pdf

medication management and adherence. The study presented in this paper addresses this gap. We outline details of an extensive requirements gathering exercise with 124 participants, including 38 PwMs, 17 informal carers, 28 formal care workers and care managers and 41 HCPs across two EU countries, Ireland (IE) and Belgium (BE). Our results focus on three key themes and a number of subthemes that emerged in relation to medication management. We outline six requirements for the design of an application to support medication self-management for PwMs, as well as to meet the needs of their supporting care ecosystem. This represents our first contribution.

A second key contribution of our work involves the use of the Behaviour Change Wheel (BCW) [12] to integrate behavioural theory into our application design. We are using the BCW approach to inform the design of the proposed medication application, to ensure requirements are translated into a meaningful digital intervention which can be evaluated. Using Michie's framework [12] alongside our requirements, we have identified target behaviours for a medication application for PwMs and their care ecosystem. We have carefully considered the impact of behaviour change, the likelihood of changing the behaviour, spillover to other important selfmanagement behaviours and ease of measurement. This novel approach is key to designing an effective, multistakeholder intervention.

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#### **BACKGROUND AND RELATED WORK**

To date, ICT to support medication management for older people has primarily focused on improving adherence through; improved information and understanding about medicines, conditions, medication regimens; communication with HCPs; medication reconciliation; adherence through reminders and alerts [5], [6], [17].

Haverhals et al. [7] interviewed 32 older adults and two family caregivers and identified five key themes relating to medication self-management: seeking reliable information, maintaining autonomy in medication treatment decisions, worrying about taking too many medications, reconciling information discrepancies between allopathic and alternative medications, and tracking and coordinating information between multiple providers. They suggest that applications to support medication management should provide reliable information on side effects and drug interactions, facilitate communication between patients and support actors and allow patients to disclose medication information to HCPs.

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Zulman et al. [23] report a study involving focus groups with 53 PwMs from a Veterans Affairs clinic, that aimed to better understand self-management and healthcare navigation challenges. In terms of medication management, issues identified included long, complicated regimens, risk of drug interactions due to multiple providers, and the patient being the one person who is always aware of their current medications. The authors' suggestions for ICT support include information to help patients identify drugdrug interactions, applications or programmes to assist with organizing the medication regimen and tools that inform caregivers about medication changes.

Applications with a single primary focus, such as electronic alerts, tele-monitoring or medication reviews alone, have not proven effective in improving medication adherence [5]. Recognition of the complex range of factors involved in medication non-adherence requires an approach that targets a range of behaviours to be changed rather than focusing on a single aspect of non-adherence [6]. The range of conditions, comorbidities and contexts experienced by older PwMs also requires health applications to be individualized or personalized to meet the needs of this widely diverse group [16], [17].

In order for a digital medication tool to be effective, a change of behaviour from current practice will be necessary; the user will need to move from their existing medication management strategy to one supported by the digital system. It is, therefore, important to design the system as an intervention to change behaviour around medication management. One major criticism of technologies that are designed to support behaviour change is that they cannot demonstrate efficacy or provide measurable outcomes, either because there is no appropriate theoretical framework for the intervention design [8] or there is no clear evaluation methodology [10]. Within the field of behavioural change (BC) there are a wide range of potential interventions that can be applied to improve peoples' health, including education, rewards, goal setting and regulation among others. Considerable work has been conducted to establish strong theoretical frameworks for these interventions [1], [13], [14] and evidence continues to emerge about these theories [20], [22]. The plethora of overlapping and diverse theories available, along with lack of clear guidance about how to select a theory best suited to the specific purpose, complicates the task of selecting an appropriate theory to inform intervention design [3].

The Behaviour Change Wheel (BCW) developed by Michie et al. [12] is the theoretical framework informing the design and evaluation of our proposed medication application. The BCW was developed, not only to aid intervention design, but also to improve the process of intervention, evaluation and theory development. The BCW is a synthesis of nineteen frameworks identified by Michie et al. [12] from the behaviour change research literature. The BCW is centred on a model of behaviour known as 'capability',

<sup>&</sup>lt;sup>2</sup> http://proact2020.eu/

'opportunity', 'motivation' and 'behaviour' (COM-B) where behaviour is part of an interacting system involving all these components (ibid.) The BCW is a practical 8-step process enabling a designer to clearly define behaviours that are the target of the intervention and then to analyse what needs to change according to the COM-B model.

Sinnott et al. [18] describe a study which used the BCW approach to develop an intervention to improve medication management for multimorbidity by GPs. The authors identified medication reviews as a target behaviour and, using the BCW, conducted a behavioural analysis as to why GPs were not engaging in this behaviour. This in turn was used to determine the intervention functions and behaviour change techniques most likely to achieve behaviour change. Applying the BCW in the design of our digital medication intervention is intended to, likewise, systematically characterise our intervention so that we can pinpoint why or how it succeeded or failed (ibid.).

The BCW is a relatively recent framework, and there is little evidence of its applicability within the field of multimorbidity management, nor until recently [14] for the design of ICT. In this paper we outline how we are using the BCW to translate our requirements into target behaviours as part of a meaningful digital intervention to assist PwMs to manage their medication, with support from their care ecosystem.

#### **METHODOLOGY**

#### **Participants**

PwM participants in both countries were recruited through a variety of sources, including HCPs, formal care organisations, living labs and various social groups for older adults. Inclusion criteria for PwMs were people over 60 years of age who were managing two or more conditions (Diabetes, Chronic Obstructive Pulmonary Disorder (COPD), Coronary Heart Disease (CHD) or Congestive Heart Failure (CHF) and Mild Cognitive Impairment (MCI)). In Ireland, 19 PwMs participated (mean age 73, age range 60-86; 11F). In Belgium 19 PwMs participated (mean age 76, range 65-89; 11F). In each country, 15 participants had two of the included conditions. Four participants in Ireland and three in Belgium had three conditions, while one in Belgium had four conditions. The most common combination of conditions was Diabetes and CHF/CHD (IE n=6; BE n=5), followed by COPD and CHF/CHD (IE n=4). The majority of PwMs (IE n=16; BE n=13) reported having conditions additional to the inclusion criteria.

Where PwM participants had an informal carer, these were also invited to take part. Other informal carers were recruited through a formal care organisation. Inclusion criteria included anyone over the age of 18 caring for a PwM with two or more of the above conditions. In Ireland, 7 informal carers participated (6F, 1M; mean age 59.57, age

range 49-74). In Belgium, 10 informal carers took part (9F, 1M; mean age 60.4, age range 36-80).

Using a snowball sampling method, HCPs were recruited through existing links in both countries. Across both regions, 11 General Practitioners (GPs) took part. Specialists included consultants and clinical nurse specialists (CNS's) of each condition, including gerontology (total specialists n=12). Other HCPs, included public health nurses (PHNs), physiotherapists, occupational therapists, a dietician, a speech and language therapist and a care coordinator (n=10). Formal care workers (n=21) and managers (n=7) were recruited through formal care organisations while pharmacists (n=8) were approached directly by researchers.

#### **Data Collection**

A mixture of semi-structured individual interviews and focus groups were conducted. The format of the data collection was dependent participant on preference/convenience. For example, PwMs with COPD or those who were mobility impaired expressed a preference to be interviewed at home rather than travelling to a focus group. All interviews and focus groups were conducted in person and were moderated by members of the research team. Four researchers in Ireland and two in Belgium conducted interviews and focus groups, and the subsequent analysis. All interviews and focus groups lasted between approximately 45 and 120 minutes, and occurred between May and August 2016.

#### **Data Analysis**

All interviews/focus groups were audio recorded and transcribed verbatim for analysis. Each transcript was reviewed by a researcher to verify the integrity of the transcription with the recording and to anonymise identifiable data. A semantic thematic analysis of these transcripts was then conducted using NVivo (Version 11). A selection of transcripts were coded by two researchers, to ensure a thorough iterative identification of a wide range of sematic themes.

#### **FINDINGS**

As the interviews and focus groups explored all aspects of multimorbidity management and integrated care, a large number of themes emerged across the data and are thus outside the scope of one paper. We focus here on the medication theme and sub-themes that emerged within it. Stakeholders are identified with the following legend, where IE represents Ireland and BE Belgium:

- 01 Person with Multimorbidity (PwM)
- 02 Informal Carer (IC)
- 03 Community HCPs
- 04 Hospital HCPs
- 05 Formal Carers or Managers (FC)

Polypharmacy is an accepted reality for older adults with multimorbidity. The PwMs interviewed reported taking between 4 and 20 different medications each day (IE

mean=12; BE mean=9). It is, therefore, not surprising that taking medication was seen as the primary method of self-management of conditions to address symptoms, avoid worsening or recurrence of symptoms, and as the main means for PwMs to be 'in control' of their health.

PwMs in our study reported largely adhering to their medication regimen. Some PwMs reported adapting prescribed regimens to suit their lifestyle and personal routine. At the same time, the medication regimen has a significant impact on PwMs' life and lifestyle, with many reporting that the requirements of their medication routine prohibited them from being able to do many things they used to or would like to do. A number of themes emerged relating to medication. These have been categorised into three main groups: management of medications, adherence and knowledge of medications.

#### **Management of Medications**

Managing medications was seen by the majority of PwMs as the main task in self-managing conditions: 'The biggest thing is to make sure I take my tablets when I should take my tablets... that's the key - if I keep that regular I don't have a problem' (IE-01-0005). For HCPs, effective management of medications was regarded as essential to effective self-care and to avoiding exacerbations or hospitalisation: '... one thing I believe that would help people that end up going back into hospital, or end up being at home safer, is a much better pathway in minding their medications' (IE-03-0002).

When asked about the main challenges in treating older people with multiple conditions, GPs overwhelmingly cited polypharmacy and medication management as the most difficult aspect of care. '... all the medications you have to give them, and managing those, and also, adjusting medication for age. It's managing those rationally, and also making sure if one thing is prescribed for one condition that it doesn't affect another' (IE-03-0005).

Pharmacists also identified adherence and education as key priorities: 'Our first priority is medicine management. The main role now is compliance, to try and get patients to continue taking their medication. And taking an action to make sure that the person understands why they are taking their medication' (IE-03-0002). Pharmacists felt they were ideally placed to play a role in supporting medication adherence 'it's a more relaxed environment, you would talk, you would ask things, you know, you would stumble across things in conversation' (IE-03-0001). This was also recognized by other HCP's 'When it comes to medication, then the pharmacist is definitely an equal partner, sometimes even better suited' (BE-03-0003).

#### Medication Routines and Organisation

Routine plays a very important role in the management of medications. PwMs tend to have a routine, both for preparing medication and taking it. This routine takes 'discipline' and can take time. PwMs typically were familiar

with the required conditions for taking their medication (e.g. time of day; before/after/with food) and most accepted the importance of taking medications according to the schedule prescribed. Pharmacists reported playing a role in helping people devise a regimen for medication management: 'We'd be involved if they were on a lot of medication. We can be involved in terms of coming up with a regime that makes it easier for them a couple of times a day when it's easy for them to take tablets' (IE-03-0004).

Many PwMs reported using blister packs to organize and support medication management. A blister pack is a box or package with a series of sealed compartments containing the medication/s for each time medications are to be taken (e.g. morning, afternoon and evening). In Ireland, blister packs are typically made up by the pharmacist, for a week or month at a time. In Belgium, however, they were mainly prepared by the PwM with support from an informal or formal carer. This preparation requires a basic knowledge about what medications need to be taken, in what dosages, and at what times.

Pharmacists and HCPs spoke about promoting blister pack usage for PwMs. Blister packs can also help pharmacists and/or family to monitor compliance with medications, by checking if all doses have been removed from the pack. This, however, requires the PwM to return their blister pack to the pharmacy, which is not currently required when requesting their next prescription. Some PwMs referred to the blister packs as aiding with medication adherence: 'if they weren't in that there (blister pack), there is no way. I definitely would forget' (IE-01-0009).

#### Medication Reviews

From our data, it appears that regular medication reviews for PwMs in the community setting are not routine practice. Only two participants in Ireland (a PwM and an informal carer) reported having had a review, while in Belgium, only pharmacists mentioned reviews. Pharmacists in Ireland mentioned that they are uncommon but felt they would be beneficial.

IE-04-0006, a CNS in a geriatrician-led clinic, reported conducting medication reviews with older PwMs: *'I do some medication management, check that they are kind of not taking two tablets for one condition or whatever when they only need one'*. An issue with this however is that it is very difficult to get an appointment with geriatric services. GPs reported not having enough time to perform medication reviews regularly as part of their workflow but said that, time permitting, a review may be initiated if a patient requested it: *'[Patients] may ask if you can take them off any [medication]. Or they come in saying they stopped it'* (IE-03-0010).

Pharmacists interviewed in both Ireland and Belgium felt they were best-placed to conduct medication reviews: 'The pharmacist setting is much easier for the patient to come in, bring all their medication in, and just make sure everything is there' (IE-03-0004).

#### Adherence

#### Forgetting to take medication

Cognitive impairment or memory loss was identified by HCPs and pharmacists as the primary reason a PwM might forget to take their medication. 'It goes well until the cognitive function starts to decline. Then sometimes it really starts to derail.' (BE-03-0007). Most PwMs also expressed worry about how ageing and the onset of impairment might affect their ability to manage medications in the future.

Changes to medications were also identified as potentially impacting adherence: Trm on 20 mg of 1 particular tablet and last month she gave me 2x10mg and she told me make sure you take two tablets instead of one, and I forgot all about it' (IE-01-0006). The notion of medication change affecting adherence was also noted by pharmacists: '... as the conditions change the tablets change and very often we find that sometimes these changes aren't necessarily communicated that well, or maybe a slight change of dose that they are unaware of, so they get confused' (IE-03-0004). It is also pertinent to note that, in addition to changes in medication, the lack of adequate communication about these changes featured as a factor impacting adherence.

Participants varied in their level of concern about forgetting to take a dose of medication. Some PwMs said missing doses made no difference, whereas others noticed the effects: '...oh God, I missed my morning tablets, it's no wonder I was so bad today' (IE-01-0017). PwMs reported different strategies for rectifying a missed dose; some add it to the next day's medication, others leave it out. These decisions appeared to be based on past experience, or on research: 'Like if you read all the leaflets that come with the tablets that says, if it is more than half way through the time you should just ignore it and go on to the next one and not double up and things like that' (IE-01-0005).

#### Self-determination vs unquestioning adherence

A strong theme of self-determination was evident in relation to medication adherence in Ireland. This is not intentional non-adherence, but rather self-awareness leading to decisions about taking medication. It reflects the PwM taking responsibility for medication decisions within what they consider 'safe parameters'. With self-determination there is a level of risk assessment based on experience, but also a depth of knowledge and understanding of the different medications being taken, their potential interactions and possible side effects. For example, two participants noted interactions between a medication that helps control blood sugar levels in those with type II diabetes and other medications: 'If you take iron and [diabetes medication] together, that is not good. There is a reaction between the two of those... so I know all of these chemical reactions, so I know what could transpire, so I have them spaced out that I take them in the right order' (IE-01-0014); 'That [diabetes medication] tablet, that has an effect on your kidneys after a while. I only found that out by aside' (IE-01-0016). One PwM reduces his aspirin intake due to side effects: 'I'm on Aspirin and I find I can get all blotchy, so I leave out an odd one. Mondays and Fridays is when I don't take them' (IE-01-0007).

This self-determination was linked to a sense of the PwM taking control of their medication, and communicating to HCPs what they want or need in relation to this. One PwM who, as noted above, experienced a change in the dosage of his medication leading him to forget to take it, said he would refuse this change in the future: 'If the chemist (pharmacist) offered me 10mg again I would refuse it, I'd wait for the 20mg you know, because it does upset the routine of taking your medication and I pay, I suffer for that' (IE-01-0006). HCPs also spoke about selfdetermination, noting that some PwMs only take prescribed medications when they feel they need them: 'some patients they are actually written up for a diuretic but they kind of only take it when their legs swell up' (IE-04-0006). PHNs noted, however, that often the PwM does not realise the impact of not taking medication, or taking it at the wrong time. While self-determination was the more dominant theme, some PwMs reported unquestioningly following their prescribed medication regimen.

In Belgium, the theme of self-determination in medication compliance was less evident; only one PwM noted explicitly requesting a certain medication from the GP. Even when PwMs showed insight into possible interactions or side-effects from medications they were taking, they did not express reduced compliance or a need to take control of their medications; most tried to comply with the prescribed medication regimen as best they could. One exception to this related to painkillers and psychotropic medication, with a preference to limit use of these types of medications reported by some PwMs 'And I take as little painkillers as possible. That's also not good for the grey mass (brain)' (BE-01-0015).

Both in Belgium and Ireland, informal carers also play a role in determining and making judgement calls around medication adherence for the PwM. Two informal carers reported making changes to the PwM's insulin dosage in consultation with the diabetic clinic by phone: 'I just ring the diabetic clinic and they say ok, higher her insulin up - eh 2 units, and ring me back in a week and we kind of monitor it that way' (IE-02-0004).

#### Support with Adherence

Most PwMs reported managing their medications themselves, while some referred to supports, such as formal carers and pharmacists. For some, it was a matter of retaining independence: 'No, no. I manage - The chemist offered [blister packs] but I manage them myself. I don't [laughs] want to go down that road yet [laughs]' (IE-01-0012). Or as stated by an informal carer about his mother

still organising her own medications, 'She does it herself, it takes a long time but we let her do it because it's part of her self-worth' (BE-02-0001). Some informal carers identified help with medication adherence as a key reason/motivation for seeking formal care support for their relative with multimorbidity.

Formal care workers identified themselves as key in supporting medication management for PwMs, through provision of reminders and prompts: 'Because we've to go in and prompt medicines in the morning - and there could be 7 or 8, 9, 10 tablets that they've to take' (IE-05-0005). Formal carers noted, however, that they often lacked information about what medications their client was taking and what the purpose of these medications were, particularly when a client's medications had been changed during a stay in hospital: 'you see the tablets, they are taking something extra or something has been taken off, and you'd say what's this tablet missing or this? Something has been changed - but you are not.. why your client has been changing from this to that' (IE-05-0008).

### **Knowledge of Medication**

#### Understanding how to take medications

While it was evident that many PwMs had a good understanding of their medication and its purpose (see Self-determination section), some were less knowledgeable: 'I take my tablets, I don't know what tablets I'm on unfortunately, but I know that some is blood pressure and there is an aspirin tablet' (IE-01-0008). HCPs and pharmacists noted the importance of knowledge on the purpose of medications and how to take them, the latter particularly in relation to COPD. A pharmacist described an example related to education around inhaler usage: It's hard to believe it but this person was actually spraying a [brand name] inhaler which is meant to go down into your lungs up their nose, for three years. And they were actually putting the [brand name] nasal spray into their mouth.' (IE-03-0001).

A COPD CNS (IE-04-0010) spoke about how the purpose of inhalers often isn't explained to people, or they haven't been told by their GP why they are on the inhaler. This can lead the PwM to take inhalers only when they get breathless, instead of taking them as prescribed. A COPD physiotherapist (IE-04-0011) estimated that only 25% of their patients take their inhalers correctly.

GPs also stressed the importance of correct use of medication and devices: 'The thing that pops immediately to my mind would be COPD in terms of inhaler technique... I remember one poor chap, ... he showed me and he went like this – squirted it as if it was a mouth spray, and I was thinking, nobody has told him how to use his inhalers. And when we taught him to use his inhalers properly, it was amazing, he was a different fellow. (IE-03-0005).

A wide range of inhalers are available, and HCPs noted that problems can arise for the PwM when a new inhaler is

prescribed, that should be used differently to their current inhaler: 'It's a huge difficulty because it's a different technique, if they don't use the technique right then they might as well just puff it out the window' (IE-04-0010). She also noted: 'some of these have a capsule you put into it [into the inhaler], so people were swallowing the capsule, because it's a tablet, and it doesn't cause any side effect but it doesn't do any good for their lungs.'

Similarly, it was noted how important it is for CHD patients to understand how to use their nitrate spray: 'The nitrate, making sure they use that properly and another thing.. it's very important, is that they're actually not standing when they take it, because it can cause the patient to actually feel light headed or possibly faint' (IE-04-0006).

#### Information to support knowledge of medications

Experiences differed in terms of the level of information that participants received from their GP regarding the medications they prescribed: 'Sometimes you get tablets and they never explain what they are. If you ask your chemist, maybe he will explain but, the doctor writes out a prescription, right, that's it. [laughs] (IE-01-0011). Pharmacists were an important source of information about medications: 'If you have a good pharmacist... That is priceless. If... you ask for information, then you get information' (BE-01-005).

Time pressures experienced by GPs were repeatedly mentioned by many stakeholders, and this may indicate a recognition that GPs may not have enough time to provide sufficient information about medications. As noted above, pharmacists felt that they are probably better placed to spend this time with patients and should probably act as the main source for this information.

Some PwMs reported difficulty reading medication information leaflets. Pharmacists also noted that reading information leaflets can be problematic, 'it's very small writing [...] unless you had very good eyesight you would never read what was written down' (IE-04-0007). Formal care workers also noted that when their clients' medications are in blister packs, the formal carer cannot read the leaflets and boxes in order to familiarise themselves with what medications their client is taking: 'Because most medications now come in blister packs, you don't get, like where before you used to be able to read the boxes and read the leaflets, we don't get that now when the medication is blister packed' (IE-05-0011).

# Maintaining lists of medications

Typically, the PwM or main informal carer is the source of information regarding medications they are on, providing this information to the HCPs and their pharmacist. Many PwMs use lists to keep an accurate overview. PwMs in Ireland and Belgium reported bringing this list to GPs, pharmacists and other HCPs. The majority spoke about how their list helps, to resolve lapses in information flow between specialist and GP's. Being repetitively asked what

medication they are on, was identified as a source of frustration for PwM's: 'This is what's repetitive [pointing to paper list of medications] is the medication, so this [paper list of meds] is my way of getting over it. I use it for the chemist, which like, the chemist says 'I wish everyone would do that" (IE-01-0013). Many PwM participants had some kind of medication list, maintained by themselves or by their informal carer, handwritten or electronically made and printed. IE-01-0013 also spoke about how she manages this list electronically: 'I make up that myself on the computer, I have is a list of conditions on that line, the medication for that condition, what level it is, and how often you take it. And I carry it in my bag as well. I always hand over my medication list, when I am at the doctor'.

GP's also reported relying on the PwM to 'own' or manage their list of medications. If the PwM has had a recent hospital or specialist clinic visit and has received a new prescription, for example, it could take 'months' for the GP to receive a letter communicating this: 'Our hospital letters can take 4 months to come to us' (IE-03-0010) '...often no letter is sent, they forget it or there is a statement at the hospital and it takes two months for the letter to be sent' (BE-03-0003).

Delays in communicating prescriptions were also highlighted by the geriatrician: 'There can be delays because of resources, there might often be a delay of several weeks between a person being seen, a letter being dictated and a letter arriving at the GP. So that's a bit of an issue as well' (IE-04-0005). The aspirations of formal care quality managers highlight the importance of this issue: 'I think if there was only one thing out of this research it's that everyone had a digital list of their prescribed medication' (IE-05-0002). Supporting the PwM to have accurate knowledge of their medication was seen by all stakeholders as critical, if they are to be empowered to manage their own medications.

#### **Summary Across Stakeholders**

In summary, all stakeholders felt that medication management is the most important aspect of managing multiple conditions. Most PwMs felt they were managing their medication intake well, and independently, requiring little support from others. This was primarily because PwMs noted having a regimen that supported adherence. Most other stakeholders reported that PwMs manage medication adherence well, but noted that the onset of cognitive impairment changes this. At this point, informal and formal carers play an important role in prompting and reminding PwMs to take their medication.

A variety of factors were noted as having potential negative impact on medication management. Frequent changes to medication, and poor communication about such changes, were highlighted by all stakeholders as causing confusion and leading to forgetting to take medication, or taking incorrect dosages. This impact is most strongly felt by PwMs and their informal carers. Formal carers, however,

also identified challenges to supporting medication prompting, whilst lack of effective and timely communication about medication changes also affected HCPs who, in turn, depend on the PwM keeping an up-to-date record of their medications.

Keeping a list is one way PwMs reported taking ownership or control of their medication management. Another was making decisions around whether or not to take certain medications – which didn't always happen in consultation with a HCP. HCPs also noted this practice of people choosing not to take certain medications. While PwMs mainly reported that this was due to potential side-effects of medications, HCPs felt PwMs might not take medications until they experience a symptom. While PwMs did not appear to see any potential danger in this practice, HCPs expressed concern that PwMs did often not have adequate information to support them in making such decisions, or understanding the potential impact.

Lack of information was cited by PwMs, informal carers, formal carers, pharmacists and HCPs as contributing to potential issues in medication management. HCPs and FCs spoke of particular problems with medication devices for COPD management being used incorrectly. All stakeholder groups highlighted challenges with either the delivery of information, for example through difficult to read leaflets, or ineffective communication of relevant information. It was evident across stakeholder groups that the pharmacist could potentially play a key role in supporting PwMs with education and information to support medication management activities.

# KEY REQUIREMENTS FOR A MEDICATION APPLICATION

A strong theme that emerged relates to the PwM 'owning' and managing their medication list, and HCPs often relying on them to provide their list of medications. This corroborates previous research, including that of Haverhals et al. [7] and Zulman et al. [23], and was evident at both sites, although there appeared to be less reliance on the PwM for this information in Belgium, perhaps due to the greater co-ordinating role played by GPs in the Belgian health context. Nonetheless, HCPs in Belgium were appreciative of people bringing their medication lists to appointments. Given the central role played by the PwM in this regard, knowledge about medications being taken, including drug names and dosages, is, therefore, important for the PwM to have. In both Ireland and Belgium, however, there was wide variation in the levels of knowledge PwMs had about their medications. In particular, lack of awareness about the purpose of medications was noted, as well as confusion resulting from frequent changes in prescriptions. This was also found by Loos et al (2014) who identified this lack of knowledge, by both PwMs and their carers, as a significant barrier to effective medication adherence and overall selfmanagement. Our findings highlight that the pharmacist is

ideally placed to play a significant supporting role in medication management, providing information to the PwM and supporting their regimen. Moreover, pharmacists reported having time to do this, and appear willing. We envisage the pharmacist could thus play a key role in the PwM's support ecosystem.

Concerns about incorrect usage of COPD medication devices arose with frequency. Poor knowledge was typically due to lack of information from HCPs or pharmacists. Formal carers are often charged with supporting the PwM in following their medication regimen, but reported that they frequently do not have access to the most recent, up-to-date list of the PwM's medications (especially after a change e.g. hospitalisation). They are also expected (by PwMs and their families) to have knowledge on medication devices such as oxygen, but this is not part of their preparatory vocational training.

The findings of this study identified six key requirements for a medication management application to support PwMs and their care ecosystem. These are: (1) Support for creating, maintaining and updating current lists of medications, where the PwM is in control and members of the care ecosystem have access; (2) Education on what medications are prescribed for different conditions or symptoms; (3) Support for managing regularly changing medication; (4) Prompts for detailed medication reviews; (5) Education and information on using medication devices, such as oxygen, nebulisers and inhalers; (6) Support for scheduling and taking medication as prescribed, particularly for those with MCI.

# **TARGET BEHAVIOURS**

Michie et al [12] argue that use of the BCW, for analysis of behaviour change, is most effectively accomplished where there are fewer target behaviours to evaluate. From the six key requirements above, three target behaviours, relating to medication management, have been identified for analysis using the BCW framework. The final targets and associated analyses are presented in Table 1. These targets were created from requirements: (1) Support for creating, maintaining and updating current lists of medications; (3) Support for managing regularly changing medication and (4) Prompts for detailed medication reviews. The three remaining requirements will be considered in the final system design but will not form part of the behaviour change intervention strategy.

Table 1 outlines the potential BCW target behaviours along with an evaluation of feasibility and impact of a digital intervention aimed at changing these behaviours. These target behaviours were identified from a series of regular consensus meetings, held over a 6 month period, between 4 researchers (across two institutions) working on behaviour change and system design for the application. As proposed by Michie, Atkins & West [12], the consensus team have carefully and iteratively considered the impact of behaviour change, the likelihood of changing the behaviour, spillover

and measurement. These have also been assessed within the constraints of current health systems in Ireland and Belgium.

Medication management for multiple conditions does not happen in isolation. The involvement of carers has already been identified as one of the most crucial factors in treatment adherence for older PwMs who may also be frail [2]. Updating and accurate maintenance of a medication list requires input from key support actors, particularly the informal carer, GP and pharmacist. An intervention that aims to change PwMs' behaviour to move from a physical/paper to a digital medication list will, therefore, also involve changing the behaviour of key support actors. The findings discussed above suggest a multi-stakeholder approach, to the design and evaluation of a digital medication management intervention, must be an important consideration in this process.

The three behavioural targets for the creation, maintenance and review of a digital medication list were selected because they are impactful, realistic and measurable for PwMs and key support actors (see Table 1). A fourth target, to initiate medication reviews through the digital tool, was considered. While such a target has a potentially large impact, the likelihood of changing this behaviour among GPs and pharmacists is unlikely without changes in the wider health systems in Ireland and Belgium. In Belgium, for example, the development of a shared medication scheme in the VITALINK system (www.vitalink.be) is a first step towards this transition. This transition will take time, and therefore such a target was considered beyond the scope of our proposed design.

#### **CONCLUSIONS AND FUTURE WORK**

We have outlined findings from focus groups and interviews with PwMs and key stakeholders in their care ecosystem. In total, 124 participants took part across Ireland and Belgium, resulting in a large, rich, qualitative data set, which is novel in its cross-stakeholder nature. We presented several themes that emerged across stakeholders, along with six design requirements and four target behaviours for a multi-stakeholder medication application.

There is no clear available evidence for the best approach to the design and development of a digital BC intervention(s) to support medication management for older adults with multimorbidity. We believe our approach represents a considerable step in this direction. Our current and future work involves re-engaging with participants across all stakeholder groups through a series of co-design workshops, to iterate on the design of the system. In parallel to this co-creation work we will continue to apply the 8-steps of the BCW framework to inform the design and evaluation of the application. The medication management application will be deployed as part of the larger ProACT system to support self-management, which will include

sensor-based symptom management with 120 PwMs and their care ecosystems across Ireland and Belgium, for a period of 12 months from late 2017. This will enable us to fully evaluate the effectiveness of our behaviour change led approach to supporting PwMs to self-manage their health and wellbeing at home.

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Potential target behaviours	Impact of behaviour change (unacceptable, unpromising but worth considering, promising, very promising)	Likelihood of changing behaviour (unacceptable, unpromising but worth considering, promising, very promising)	Spillover score (unacceptable, unpromising but worth considering, promising, very promising)	Measurement score (unacceptable, unpromising but worth considering, promising, very promising)
1. PwM to create digital list of medications	Promising The creation of a digital medication list was identified as a key requirement to address the complexity and errors that currently occur in medication management for people with multimorbidity	Promising There may be initial barriers (knowledge, preference, accessibility) to changing older adults behaviours from physical handwritten lists on paper to a digital list	Very Promising The use of a digital medication list could have positive spillover to other important behaviours for medication management such as adherence.	Very Promising Tracking if a PwM has changed their behaviour managing their medication from a physical paper based one to a digital list is easily recorded through the proposed medication application.
2. PwM maintain and update list of current medications	Very Promising A tool that could support PwMs updating their medication lists could help with engagement with overall self-management skills.	Promising There are similar barriers in terms of adopting the technology (inclusive design should ensure that maintaining and updating the list is accessible and easy to use)	Very Promising Maintaining an up to date and accurate medication list could have positive spillover to address medication errors that presently occur for people with multiple conditions	Promising Measuring whether a person's digital medication list has been maintained and updated can be easily measured through the proposed application. However, whether the list contains an accurate current list would need to be confirmed by other key actors such as a pharmacist and GP
3. GP and Pharmacist and other relevant actors to regularly review digital medication lists	Very Promising Maintaining and updating an accurate list verified by key support actors will have significant impact on medicating management and adherence	Promising Ownership of medication lists currently lies with the PwM. If this was a digital list it would be easier to share and update with key actors electronically or by bringing the device to their appointments	Very Promising The involvement of key actors in medication management could have positive spillover to address the errors that presently occur for people with multiple conditions	Very Promising This could be confirmed and measured by a checkbox within the app
4. GP and Pharmacist to initiate medication reviews based on regular reviews of digital list	Very Promising Medication reviews were highlighted as important to enhance overall self- management and to improve adherence.	Unpromising but worth considering Behaviour to initiate medication reviews will require changes in wider healthcare context influenced by cost, policy and support for integrated care.	Very Promising Regular medication reviews could have positive spillover to other important behaviours for medication management such as adherence.	Unpromising but worth considering It may be complex to ascertain whether the initiation of medication reviews was triggered by the digital list or by the policy of the HCP or pharmacist

Table 1. Target Behaviours for the design of a Medication Application as a digital intervention to enhance medication management for PwMs and their care ecosystem

#### **REFERENCES**

- 1. Abraham, C., Michie, S. A taxonomy of behaviour change techniques used in interventions. In *Health Psychol*, 27, 3, (2008).
- 2. Bauer, M., Fitzgerald, L., Haesler, E. and Manfrin, M. Hospital discharge planning for frail older people and their family. Are we delivering best practice? A review of the evidence, *Jnl of Clinical Nursing*, 18, (2009).
- 3. Davis, R., Campbell, R., Hildon, Z., Hobbs, L., Michie, S. Theories of behaviour and behaviour change across the social and behavioural sciences: a scoping review. In *Health Psychology Review*, 9, 3, (2015).
- 4. Doos, L., Bradley, E., Rushton, C., Satchithananda, D., Davies, S. and Kadam, U. Heart failure and chronic obstructive pulmonary disease multimorbidity at hospital discharge transition: a study of patient and carer experience. *Health Expectations*, 18 (2014).
- 5. Granger, B. and Bosworth, H. Medication adherence: emerging use of technology. *Curr Opin Cardiology*, 26, 4, 279-287, (2013).
- Grindrod, KA., Li, M. and Gates, A. 2014. Evaluating user perceptions of mobile medication management applications with older adults: A usability study. *JMIR* mHealth and uHealth, 2, 1 e11 (2014).
- 7. Haverhals, L., Lee, C., Siek, K., Darr, C., Linnebur, S., Ruscin, M., et al. Older adults with multimorbidity: Medication management processes and design implications for personal health applications. *Journal of Medical Internet Research*, 13, (2), (2011).
- 8. Hekler, E.B., Klasnja, P., Froehlich, J.E and Buman, M.P. Mind the theoretical gap: Interpreting, using and developing behavioural theory in HCI research. In *CHI*, (2013).
- 9. Hughes, L., McMurdo, M. and Guthrie, B. 2013. Guidelines for people not for diseases: the challenges of applying UK clinical guidelines to people with multimorbidity. *Age and Ageing*, 42, 1 (2013), 62-69.
- 10. Klasnja, P, Consolvo, S. and Pratt, W. How to evaluate technologies for health behaviour change in HCI research. In *CHI*, (2011).
- 11. Marengoni, A. and Onder, G., Guidelines, polypharmacy and drug-drug interactions in patients with multimorbidity. In *Br Med J*, 350, (2015).
- 12. Michie S, Atkins L, West R. The Behavioural Change Wheel: A Guide to Designing Interventions. Silverback Publishing. Great Britain. ISBN: 978-1-291-84605-8, (2014).
- 13. Michie, S., Hyder, N., Walia, A. and West, R. Development of a taxonomy of behaviour change techniques used in individual behavioural support for smoking cessation. In *Addictive Behaviors*, 36, (4), (2011).

- 14. Michie, S., West, R. A guide to development and evaluation of digital behaviour change interventions in healthcare. Silverback Publishing, (2016).
- Rijken, M., Struckmann, V., Dyakova, M., Gabriella, M., Rissanen, S., van Ginneken, E. ICARE4EU: Improving Care for People with Multiple Chronic Conditions in Europe. *Eurohealth Incorporating Euro Observer*, 19, 3, (2013).
- 16. Sav, A., Kendall, E. McMillan, S., Kelly, F, Whitty, J., King, M. and Wheeler, A. 'You say treatment, I say hard work': treatment burden among people with chronic illness and their carers in Australia, *Health and Social Care in the Community*, 21, 6, (2013).
- Siek, K., Ross, S., Khan, D., Haverhals, Cali, S. and Meyers, J. 2010. Colorado care tablet: the design of an interoperable Personal Health Application to help older adults with multimorbidity manage their medications. *Journal of Biomedical Informatics*, 43 (2010), S22-S26.
- 18. Sinnott, C., Mercer, S., Payne, R., et al. Improving medication management in multimorbidity: Development of the MultimorbitidY Collaborative Medication Review and Decision Making (MY COMRADE) intervention using the Behaviour Change Wheel. In *Implementation Science*, 10, (2015).
- 19. Starsfield, B., Shi, L., Macinko, J. Contribution of primary care to health systems and health. In *Millbank Q*, 83, 3, (2005).
- Tuah, NAA, Amiel, C., Quershi, S. et al.
   Transtheoretical model for dietary and physical exercise modification in weight loss management for overweight and obese adults. In Cochrane Database of Systematic Reviews, 10, (2011).
- Viswanathan, M., Golin, et al. Medication adherence interventions: comparative effectiveness. Closing the quality gap: revisiting the state of the science. Evidence report No. 208. AHRQ Pub. No. 12-E010-EF. Rockville, MD. Agency for healthcare research and quality (2012).
- 22. Williams, S.L. and French D.P. What are the most effective intervention techniques for changing physical activity self-efficacy and physical activity behaviour and are they the same? In *Health Education Research*, 26, (2011).
- 23. Zulman, D., Jenchura, E., Cohen, D., et al. How can eHealth technology address challenges related to multimorbidity? Perspectives from patients with multiple chronic conditions. In *Journal of General Internal Medicine*, (2015), pp. 1063-1070.