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BMJ Open 'Everyone should know what they're on': a qualitative study of attitudes towards and use of patient held lists of medicines among patients, carers and healthcare professionals in primary and secondary care settings in Ireland

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ABSTRACT

Objectives Managing multiple medicines can be challenging for patients with multimorbidity, who are at high risk of adverse outcomes, for example, hospitalisation, Patient-held medication lists (PHMLs) can contribute to patient safety and potentially reduce medication errors. The aims of this study are to investigate attitudes towards and use of PHMLs among healthcare professionals (HCPs), patients and carers.

Design Qualitative study based on 39 semistructured telephone interviews.

Setting Primary and secondary care settings in Ireland. Participants Twenty-one HCPs and 18 people taking medicines and caregivers.

Methods Telephone interviews were conducted with HCPs, people taking multiple medicines (5+ medicines) and carers of people taking medicines who were purposively sampled via social media, patient groups and research collaborators. Interviews were transcribed and thematically analysed based on the Framework approach, with the Consolidated Framework for Implementation Research and Theoretical Domains Framework.

Results Three core themes emerged: (1) attitudes to PHML. (2) function and preferred features of PHML and (3) barriers and facilitators to future use of PHML. All participating (patients/carers and HCP) groups considered PHML beneficial for patients and HCPs (eq. empowering for patients and improved adherence). While PHML were used in a variety of situations such as emergencies, concerns about their accuracy were shared across all groups. HCPs and patients differed on the level of detail that should be included in PHML. HCPs' time constraints, patients' multiple medicines and cognitive impairments were reported barriers. Key facilitators included access to digital/compact lists and promotion of lists by appropriate

Conclusions Our findings provide insight into the factors that influence use of PHML. Lists were used in a variety of settings, but there were concerns about their accuracy. A range of list formats and encouragement from key HCPs could increase the use of PHML.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study included a range of viewpoints from a diverse sample of healthcare professionals (HCPs) and non-HCPs.
- ⇒ Established frameworks were used to comprehensively assess attitudes towards and use of patientheld medication list (PHML).
- ⇒ Limitations include the requirement of conducting telephone interviews during the COVID-19 pandemic, which may have reduced contextual and nonverbal data.
- ⇒ Individuals with distinct opinions about PHML may have been motivated to participate so a more biased viewpoint may have been captured.

BACKGROUND

Medication-related harm has been identified internationally as a key area for improvement in all healthcare settings. In 2017, the WHO identified medication safety as the theme of its third Global Patient Safety Challenge and aims to reduce the level of severe avoidable harm related to medication by 50% globally in the next 5 years. Polypharmacy (five or more medicines) and multimorbidity are associated with increased risk of medicationrelated harm and often result in poorer health outcomes for patients. 1-3 Patients with polypharmacy and multimorbidity can experience many transitions of care; multiple interactions with different healthcare professionals (HCPs) and numerous transfers of information about their medicines across healthcare systems for example primary care to secondary care.⁴ Systematic reviews have reported discrepancies between medication lists in primary and secondary healthcare





sectors, with deficits in transferring information across healthcare settings resulting in medication errors.^{5 6} These discrepancies can potentially cause harm and may persist as long-term medication errors.^{7 8}

A potential solution to deficits in communication across healthcare systems is individual patient or carer involvement in managing their medicines. 910 Supporting patient participation in managing medicines has numerous benefits: improving information transfer, reducing errors, empowering patients and leading to improved health outcomes. 9 11 There is evidence that patients can have a crucial role in identifying and managing medication errors during care transitions. ¹² Many patients benefit from keeping a list of their medicines, ^{13–21} as a memory aid or assisting communication with HCPs across care settings. 13 18 However, significant barriers to using patient held medication lists (PHMLs) have been identified including lack of awareness among patients and carers of the purpose and value of keeping medication lists. 13 15 While some research has been conducted on how PHML are perceived across medical and non-medical populations, 13-21 the optimal method for supporting patients and implementing the widespread use of PHML in clinical care and during healthcare transitions remains a challenge. The Irish Health Service Executive (HSE) National Quality Improvement team is in the process of introducing a national medication safety campaignthe 'Know Check Ask' (KCA).²² The key component of this campaign is the use of a medicines list: encouraging everyone who takes medicines regularly to keep an up to date list.²² To inform implementation of the campaign, people's views on the role of PHML in routine medication management are required.

The aim of the study is to examine attitudes to PHML among patients, carers and HCPs and investigate how PHML are routinely used. A secondary objective is to identify barriers and facilitators to widespread integration of PHML in healthcare.

METHODS

Study design and participants

Semistructured interviews were conducted with patients taking multiple medicines, carers and medical, nursing and pharmacy staff (community and hospital based). Social media, patient and carers groups and contacts within the research group were used to obtain a purposive sample of patients prescribed multiple medicines (5+ medicines) with at least one chronic long-term illness and a separate sample of carers, unrelated to recruited patients, who care for people who are prescribed 5+ medicines. Sampling strata were age, gender and region. Patients with cognitive/severe functional impairment and non-English speakers were ineligible. As is standard practice within qualitative research, sample size sufficiency was based on saturation parameters as in previous research studies. Transcripts were reviewed while interviews were taking place to assess data adequacy. Recruitment

ended when saturation was reached, that is when no new information emerged.²¹ A purposive sample of HCPs including anyone/group involved with prescribing of medicines in Ireland, medicine administration and/ or information provision (general practitioners (GPs) hospital doctors, pharmacists and nurses) was generated through social media, emails/newsletters from the Irish College of General Practitioners, Royal College of Physicians of Ireland and the Pharmaceutical Society of Ireland and contacts within the research group. Sampling strata were age, gender, staff grade and region. Interested participants received an information leaflet and consent form and interviews were arranged. PHMLs were defined as any editable tool carried by patients; paper or electronic or based on documents from healthcare providers; created solely by patients or coproduced by patients and HCPs for example printed repeat medication lists, medication diaries and mobile applications.

Implementation frameworks

The Consolidated Framework for Implementation Research (CFIR) and the Theoretical Domains Framework (TDF) are established frameworks that identify the theoretical and evidence-informed constructs at organisational and individual levels, which influence behaviour. 23 24 They have been used to develop and evaluate interventions in a variety of healthcare settings.^{25–27} They were selected as appropriate tools to be used in combination to comprehensively assess patient level and system level factors that influence use of PHMLs. The CFIR has 39 constructs associated with successful implementations across five domains: intervention characteristics, outer setting, inner setting, characteristics of individual and process.²³ The TDF is a synthesis of 33 theories of behaviour change clustered into 12 domains and provides a theoretical lens to view the cognitive, affective, social and environmental influences on HCP and patient's behaviour.²⁴

Interviews

Semistructured topic guides were developed from literature review and informed by the CFIR and TDF (see online supplemental file). Signed consent forms were returned by all participants before interviews. Interviews were conducted by phone with a postdoctoral researcher (BO'D), between February and August 2021. Verbal consent to record the interviews was obtained, recordings were transcribed verbatim and anonymised and made available for participants' feedback/correction.

Data analysis

Thematic analysis was conducted based on the Framework approach, with CIFR and the TDF informing the analysis framework.²⁸ The 12-domain TDF was used for the purpose of this study. An overview of the data set was initially obtained and after familiarisation, investigators (BO'D and CC) independently coded 10% of interviews. Results were then compared and discussed to

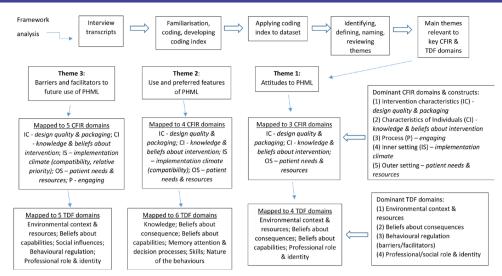


Figure 1 Flow diagram of coding process – framework analysis. Thematic analysis was conducted based on the framework approach, with the Consolidated Framework for Implementation Research (CFIR) and the Theoretical Domains Framework (TDF). Key/dominant domains were identified, and each domain was grouped into overarching themes. Five dominant CFIR and four dominant TDF domains were identified, leading to three overarching themes: (1) attitudes to patient held medication lists (PHMLs); (2) function and preferred features of PHML; and (3) barriers and facilitators to future use of PHML.

Patient and public involvement

Key stakeholders were involved in the conceptualisation of the study. We invited the patient and public involvement (PPI) consultative group to provide feedback on recruitment methods and study materials including topic guides, recruitment documents, information sheets, consent forms, etc.

RESULTS

Characteristics of study participants

A total of 39 interviews (18–68 min in duration; mean 35 min) were conducted with 21 HCPs and 18 patients and carers. The majority of interviewees were female (n=29, 74%) with a median age of 60 years (IQR=52–68) for patients, 55 years (IQR=48.5–57) for carers and 45 years for HCPs (IQR=37–48) (see table 1).

Summary of overarching themes, CFIR and TDF domains

Three overarching themes were identified: (1) attitudes to PHML; (2) function and preferred features of PHML;

and (3) barriers and facilitators to future use of PHML. Within these themes, five dominant CFIR domains were identified with associated constructs: (1) intervention characteristics – design quality and packaging, adaptability; (2) characteristics of individuals – knowledge and beliefs about intervention; (3) process – engaging; (4) inner setting – implementation climate, and (5) outer setting – patient

Table 1 Characteristics of participants – HCP (n=21) and patient/carers (n=18)

	Frequency	
Characteristics	HCP (n=21)	Patients/carers (n=18)
Gender, n (%)		
Male	6 (29)	4 (22)
Female	15 (71)	14 (78)
Age (years), n (%)		
<40	9 (43)	1 (6)
40–65	11 (52)	15 (83)
65 and older	1 (5)	2 (11)
HCP role, n (%)		
Doctor	8 (38)	N/A
Pharmacist	9 (43)	N/A
Nurse	4 (19)	N/A
Region, n (%)		
East	9 (43)	3 (17)
West	5 (24)	7 (39)
South	7 (33)	8 (44)

*All patients used PHML.

HCP, healthcare professional; N/A, not applicable; PHML, patientheld medication list.



needs and resources. Twelve TDF domains were identified with four domainst domains: environmental context and resources; beliefs about consequences; behavioural regulation (barriers/facilitators) and professional/social role and identity.

Summary of subthemes within overarching themes

Within the overarching themes, numerous subthemes were identified. Each of the overarching themes and related subthemes are described further and where appropriate, illustrative anonymised quotes are included (see online supplemental table 1).

Attitudes to PHML

Participants expressed both positive and negative attitudes to lists that mapped onto three CFIR domains and four TDF domains (see online supplemental table 1.

All interviewees positively assessed lists, believing them to have multiple benefits for patients, carers and HCPs. The three groups believed that lists were empowering for patients, in particular knowing what medicines they were taking, understanding why they were taking them as well as the importance of having a record of their medicines on their person. It was also felt that keeping a list increased awareness of the purpose of their medicines could improve adherence. Lists helped them to manage multiple/changing medicines across different healthcare settings and were identified as beneficial in emergencies, out of hours services, at initial diagnoses and in transitions across healthcare settings.

All groups believed that lists could assist patient/ HCP interactions, reduce confusion/stress of emergency admissions or improve communication during consultations:

[E]very time you go to your cardiologist they ask what medications you're on... I always find that I can just give them that [list]. (DS300064, patient)

HCPs also identified additional clinical advantages such as reductions in medicine errors and unused/wasted medicines. They highlighted the issue of excess medicines for many patients as a result of poor or sporadic adherence.

Negative attitudes were also expressed; all groups had concerns about the accuracy of lists and were aware that many older patients could struggle to keep lists up-to-date. Most HCPs had encountered inaccurate lists and often used visual cues to assess the accuracy of lists; lists with worn/creased appearance, numerous errors or crossed out texts created doubts about accuracy and increased their scrutiny. However, HCPs described the steps they took to check/confirm lists as part of their professional practice:

I wouldn't have an issue with that [accuracy]. Like I'm not going to prescribe off a list that a patient comes in with. I'm going to check...I mean it's good practice. (DS300045, hospital nurse)

HCPs also had concerns about the impact of stigma on use of lists:

[T]here's still a lot of stigma around mental health conditions...so that could potentially be a problem, people might leave that off the list. (DS300053, pharmacist)

HCPs supported PHML and considered them to be useful tools; however, they also considered that lists were not extensively used by their patients. Some HCPs reported that only a minority of patients produced lists when prompted/questioned about their medicines during consultations.

Function and preferred features of PHML

This theme included the following factors: variation in use of lists, evolving list function (multiple, adapted/customised lists), varied information needs and HCP support for lists in their practice. These factors mapped onto four CFIR domains and six TDF domains (see online supplemental table 1). All patients that were interviewed used lists and identified some features that facilitated that use: customised lists and simple lists with minimal information.

Most of the patients reported they wanted to know what medicines they were taking, and the majority kept a list as part of their routine medication management. They used lists in variety of ways and found practical benefits, for example, when medicines were changing, while travelling or in hospital:

I've used it [list] quite a number of times now, I was in hospital there recently, quite a number of times I used it, it's a very, very valuable thing to do. (DS300054, patient)

Among those using lists, the function of lists evolved over time. Some patients reported initially using lists as a short-term memory aid until they progressed to a more stable medication regime. Many patients and carers reported that they used multiple lists, creating numerous versions, both paper based and digital. This replication ensured they would have access to their list when needed. Patients were confident in their ability to maintain their lists and provided detailed descriptions of how they had customised their lists to suit them:

I have the little stick-on labels that the pharmacist puts on the pack, I have all those on a piece of paper, folded up and it's in my wallet. (DS300061, patient)

Many carers also used lists that they had adapted from prescriptions or from blister packs.

There were some differences between patients and HCPs on the level of information—in terms of content and detail—that should be included in PML. Some patients wished to keep their lists simple and easy to use with minimum information:

So I suppose you can make it as easy or as complicated as you like but I just list them and list the dosage, the strength and that's it. (DS300046, patient)



In contrast a lack of detailed information in a number of lists was an issue for most HCPs. They were concerned that lists may not reflect over-the-counter or herbal medications:

[P]eople don't look at stuff that they get in a health food shop or that they buy online as a medicine because its herbal... they're the ones that they don't tell you about. (DS300065, GP)

There was agreement across groups that the desire for general information on medicines can vary; some patients want to know everything while others just require basic information about their medicines. All HCPs, patients and carers believed that effective patient/HCP communication was needed to ensure appropriate information was provided:

I suppose people are looking for different things... So I suppose it's to get the right balance. (DS300046, patient)

Many patients described positive engagement with HCPs about medicines, who they felt were open to being asked about medicines and saw lists as useful tools for managing medicines. Some HCPs reported inclusion of lists in their routine consultations particularly with their elderly patients.

Barriers and facilitators to future use of PHML

Across the groups, a number of barriers to using medicine lists were commonly reported: time constraints, difficulty in maintaining lists for particular patients and confusion about generic medicines. All groups identified similar facilitators: encouragement from key HCPs and access to multiple types of lists formats. Some facilitatory factors reported by patients and carers included patients' confidence in their self-efficacy to maintain accurate lists, the role of internal and external strategies and social support from family in managing medicines. Barriers and facilitators mapped onto five CFIR domains and five TDF domains (see online supplemental table 1).

Barriers and facilitators to using medicine lists recognised across all groups (HCPs, patients and carers)

There were similarities across groups in reported barriers to patient held lists. The most frequently reported practical barrier across the groups was HCPs' lack of time:

I think it's all part of the whole how busy we are and there would be an awful lot to squash into the consultation...but a lot of the time you are time constrained. (DS300067, GP)

All the groups (HCPs, patients and carers) reported that particular groups such as older patients, those with cognitive impairment, literacy issues or those on multiple/changing medication would have difficulties with keeping medicine lists. All groups believed that many older patients accepted the authority of HCPs and would not question them about their medicines. In addition, they

all expressed their concerns about the confusion generic medicines can cause for patients and carers:

[T]hey just don't know what they're taking to be honest with you, you know the elderly people get very confused with the generics. (DS300087, public health nurse)

There was agreement across all the groups that key HCPs—particularly pharmacists—had an important role in facilitating use of lists. GPs and public health nurses were also mentioned as trusted HCPs that could engage with patients and carers to use lists.

HCPs, patients and carers believed that practical tools such as compact (wallet-sized) versions of patient lists or digital options (phone app) could increase their use. However, all groups were aware that digital resources could exclude many older patients who might not use a phone app/have smart phones.

Barriers and facilitators to using medicine lists relevant to patients and carers

Generally, patients reported they were confident in their ability to maintain their lists, and this self-efficacy in managing medicines was often linked to internal and external strategies. Internal strategies could involve cognitive activities such as linking task with routine behaviours, for example, updating lists after each GP visit and taking tablets at meal times. Patients and carers also established external strategies to support adherence: medication lists, pill box organisers, blister packs, verbal reminders from family or memory aids with audio/visual cues.

Patients and carers described the important role that family support had in medical management, which included accessing information on medicines or creating lists:

I have a list of my drugs that I take, the tablets I take and [spouse] put it on my phone just in case I haven't got it on me. She put it into my phone. (DS300063, patient)

Patients identified a key facilitator of HCP communication about medicine and the value of lists: using simple non-medical language that the patient can understand:

... tell people why and speak to them in their own language. (DS300061, patient)

Carers supported lists as practical aids but highlighted a general lack of engagement with them by HCPs on the benefits of lists for caregivers. They also identified specific concerns about privacy and right to control of lists:

The information should be in the person's house and not taken away by the carer. That's my only concern. (DS300080, carer)

Barriers and facilitators to using medicine lists relevant to HCPs

The majority of carers used blister packs and considered them a valuable resource. However, some HCPs identified



them as potential barriers and reported their reservations that blister packs could reduce patient knowledge and potentially led to errors:

I would see blister packs as a big source of medication errors. The patient no longer knows what the medicines are for at all. And doesn't have an idea of their names anymore at all either. (DS300059, GP)

Generally, HCPs believed they had the necessary skills to engage with patients on medicine lists. They focused on the value of regular medication reviews to reduce confusion about medicines and identify unused medicines/errors. They also highlighted the key role of medication counselling, both structured and opportunistic:

[I]f there's a document there that's been filled in by a doctor and if it's given to the person, they will have that... So it will be...quite opportunistic (DS300043, hospital doctor)

DISCUSSION

This study explored attitudes and use of PHML among HCPs, patients and carers of those taking medicines. We identified three key themes: (1) attitudes to PHML, (2) function and preferred features of PHML and (3) barriers and facilitators to future use of PHML that linked to five dominant CIFR domains and four TDF domains. Patient and system level influences that can inhibit and promote use of lists were identified using the CFIR and TDF. The frameworks provide a platform for the refinement of evidence-based interventions, such as the KCA, to facilitate behaviour change. Links can be made from dominant CFIR and TDF domains to tools for designing behavioural change interventions such as the Behavioural Change Wheel (BCW) and Behavioural Change Taxonomy (BCTT). 31 32 The BCW has nine intervention functions that can be used to enable behaviour change, for example, education, while the BCTT lists the techniques that can be used to deliver these functions such as feedback and social support. 31 32 Pertinent intervention functions and supporting policies to promote use of PHML in the future can thus be identified.

Overall, all groups reported a range of perceived benefits—both practical and psychological—from using PHML. These included empowering patients to manage their medicine safely, aiding memory, improving adherence and improving communication during patient/HCP interactions. This is similar to other studies illustrating benefits as well as beliefs among patients, carers and HCPs that accurate lists were a valuable tool in improving medication reconciliation and patient safety. ¹⁵ ¹⁷ ²⁰

An interesting finding related to the day-to-day use of PHML across settings. It has been previously established that many patients have some type of medicine list when admitted to hospital. ^{15–22} We found that patients and carers had used PHML to bridge information gaps in a variety of healthcare settings and during care transitions.

However, our research also identified further use of medicine lists by patients and carers in a range of settings: routine medical appointments, emergencies, hospital discharge, outpatient clinics, when medicines were changing, while travelling, during respite care and when the main carer was absent.

A key finding of this study was related to the preferred features of PHML, which suggests a divergence between patients and HCPs on the amount of information that should be included. Some patients believed a simple list with minimum information was easy to use. This contrasted with concerns among HCPs that lists with insufficient information may not reflect patients' adherence or list all medicines that are being taken. Non-adherence to prescribed medicines is a significant issue in polypharmacy, particularly among older patients,³³ and patients with multimorbidity frequently manage complex medication regimes. Our findings suggest that a variety of list formats, such as compact version and paper/digital version with additional fields for more detailed information, could encourage patients to include all the medicines they are taking. Access to a range of formats could help address the divergence of opinion between patients and HCPs in relation to list content.

All groups had concerns about the accuracy of lists and identified specific barriers to their use among older patients. Older patients taking multiple medicines are likely to experience benefits from using medicine lists.²¹ They can be poorly informed about their medicines and often not understand their increased risk of adverse drug reactions.³⁴ However, all groups in this study believed that older patients could struggle to keep their lists accurate and up to date. These concerns are supported by studies among older patients at hospital admission that found medicine lists can display poor accuracy when compared with pharmacy records, with many older patients taking additional medicines or not listing dispensed medicines.^{22 33 35} Support from HCPs who prioritise older patients with multiple medicines for regular reviews and support from families and caregivers in maintaining accurate lists could benefit older patients and improve healthrelated quality of life. 22 35 36

Consistent with previous research, ¹⁵ ³⁷ our findings suggest agreement across all groups that HCPs, specifically pharmacists, had a key role in encouraging use of PHML. As in previous studies, ³⁸ patients identified the use of simple non-medical language by HCPs to explain medicines to their patients as an important facilitator. These findings suggest that trusted HCPs such as pharmacists could have an essential role in promoting PHML. However, it should be noted that hospital pharmacy staff who had not received training about patient held medicine information tools (eg, 'My Medication Passport') lacked confidence to promote them. ¹⁸ Therefore, appropriate training and guidance about PHML, with a focus on providing clear, simple information, is essential for pharmacists.

Social support was a significant factor for patients and carers in creating medicine lists. Our study indicated that



family members/carers often encouraged patients to use lists or some family members/carers had responsibility for keeping accurate lists of patients' medicines. This is consistent with previous research that found that family support can increase medicine adherence and medicine management generally transfers to family carers when cognitive function decreases. Similar to other studies, our findings indicate that effective medication counselling, structured (eg, medication review) or opportunistic (eg, routine dispensing), can increase patients' use of lists. In this context, peer support from colleagues could encourage less experienced HCPs to identify opportunities during everyday practice to engage with patients about PHML.

Strengths and limitations

A major strength of this study are the perspectives that have been gathered from a wide range of relevant participants: patients, carers and HCPs. However, it should be noted that those who were interviewed were motivated to participate and may have distinctive opinions about PHML. Efforts were made to address selection bias with a diverse group of participants with a variety of clinical experience and health conditions. However, there were some challenges related to the COVID-19 pandemic: recruiting patients and carers proved difficult and resulted in lower numbers in the non-HCP group compared with the HCPs. Initial plans to conduct focus groups also had to be amended, and all interviews were conducted by telephone, which may have compromised rapport with the loss of non-verbal cues.

Implications for practice and policy

Our findings have implications for medication safety campaigns such as the HSE's 'Know Check Ask', which empower patients and carers to engage with their medicines. They suggest that future implementation and adoption of such campaigns into clinical practice may be improved by addressing shared concerns about accuracy and supporting key HCPs in encouraging patients to keep lists. Effective promotion of PHML by HCPs as a beneficial patient tool will require appropriate training. Practical strategies to increase the accuracy of lists could include prioritising older patients with multiple medicines for medicine reviews, opportunistic medication counselling or encouraging family members to support patients in keeping up-to-date lists.

CONCLUSION

This study comprehensively assessed the factors that can influence attitudes towards and use of PHML. It offered new insights into the use of lists across a range of settings and identified shared concerns among HCPs and non-HCPs about list accuracy. Another novel finding was the divergence in opinions between patients and HCPs on the level of information that should be included in lists.

Future refinement of evidence-based interventions that addresses these factors could increase the use of PHML.

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Patient consent for publication Not applicable.

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