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Public Engagement Workshop:
How to Improve Medicines for Older People

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Commentary

Public engagement workshop: How to improve medicines for older people?

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A B S T R A C T

Public engagement in medication management has become more and more important in promoting population health. A public engagement workshop attended by 78 members of the geriatric community, family carers as well as professionals from academic research, industry and regulatory agencies entitled ‘How to improve medicines for older people?’ took place on the 2nd July 2013 at the University College London (UCL) School of Pharmacy. The main aim of the event was to provide a dynamic environment for information exchange and to identify ways of improving current and future geriatric drug therapy. The day opened with presentations from UCL School of Pharmacy researchers on the use of medicines at home, formulations, administration devices and multi–component compliance aids (MCAs) whilst a representative from UCL Interaction Centre gave an insightful presentation on human errors and resilience strategies regarding medication use. These opening presentations encouraged participants to share their own experiences as well as initiating a lively debate. Following the plenary presentations, the workshop was divided into 8 groups for parallel discussion session. These opinion sharing sessions witnessed fruitful discussions between patients, carers and researchers. The day closed with a panel session of representatives from the European Medicines Agency (EMA), the Medicines and Healthcare products Regulatory Agency (MHRA), the Geriatric Medicines Society and Guy’s and St. Thomas’ NHS Foundation Trust (GSTT). Participants were encouraged to voice their questions, concerns and recommendations about medications. The main concern expressed by both patients and carers from the workshop were (but are not limited to) formulation changes, MCA accessibility difficulties, interactions of different medicines, carers’ concerns with the administration of medicines and not having enough knowledge of services provided by community pharmacists i.e. medicines use reviews (MURs) or new medicine service (NMS). Overall, this workshop created a useful forum for members of the geriatric community, their carers as well as research and industrial professionals to have an input in the improvement and management of geriatric drug therapy and this event also provided an excellent opportunity for the researchers to share the latest research innovations with attendees.

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1. Introduction

Research Councils UK (RCUK) are of the belief that “engaging the public with research helps empower people, broadens attitudes and ensures that work of universities and research institutes is relevant to society and wider social audiences” (RCUK, 2013). A concordat entitled “Concordat for Engaging the Public with Research” was developed in March 2010 by RCUK outlining the expectations and responsibilities of research funders with respect to public engagement with a view to help embed public engagement in universities and research institutes. The concordat’s key principles are (RCUK, 2013):

i. UK research organisations have a strategic commitment to public engagement;
ii. researchers are recognised and valued for their involvement with public engagement activities;

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iii. researchers are enabled to participate in public engagement activities through appropriate training, support and opportunities;
iv. the signatories and supporters of this concordat will undertake regular reviews of their and the wider research sector’s progress in fostering public engagement across the UK.

The principles outlined above were the drivers for the public engagement event ‘How to improve medicines for older people?’ at the UCL School of Pharmacy. The workshop was funded by a UCL Beacon Bursary and received tremendous support from both the UCL Public Engagement Unit and Age UK London. Parkinson’s UK and Alzheimer’s Society also gave their support to the event.

Patients and caregivers should be given an opportunity to voice their perspectives at various stages of health research from taking part in prioritisation discussions, grant applications, study set-up, process and dissemination. Healthcare professionals and researchers should collaborate with patients in decision-making to enable them to discuss their own experiences and make suggestions about ways of improving healthcare services and medicines management.

Life expectancy is increasing so the number of older people is growing rapidly, leading to a rising demand for geriatric care. However, the research in medicines for older people is limited. Older persons’ views should be pivotal in defining the priorities of ageing research. Many family members are often responsible for helping their relatives to take their medicine, so carers were also invited to the workshop. Older people attended the workshop primarily to learn more about safe use of medicine use and management, but also because they wished to take part in discussions about errors/difficulties with medicines as well as resilience strategies/solutions regarding medicine use. This paper is a reflection on older people’s and carers views as to how to improve medicines as shared in the public engagement workshop.

2. Summary of plenary presentations

2.1. The use of medicines at home

Sometimes, in primary care patients are requested to schedule and manage their own complex therapies independently. However, many people who take medicines every day receive help from family and friends. Even if the level of support provided is fairly minimal, nevertheless it is important. Taking medicines or helping others with medicines can present problems and concerns for carers. Different storage places in the home, various formulations and pack sizes of formulations, variable need for regular and ‘as required’ medicines, complex or frequent dosing regimens may cause difficulties. There may be problems with remembering doses, opening packages, cutting up tablets, administering eye drops or encouraging people to take medicines. Patients and carers have views and concerns about medicines related to their effectiveness, side effect profile, concomitant therapies and generic drug products. In particular any change in the routinely administered drug product could confuse and concern the older patient. In the home setting, there is the risk that the patient and/or carer could modify the treatment. For example, carers could decrease the dose due to side effects experienced or cut the tablet up for ease of administration which could change the efficacy and/or safety of the drug. Hence, assistance with the use of medicine at home is required to optimise therapeutic treatment of older patients.

2.2. Formulations and administration devices

The geriatric population comprises a heterogeneous group with varying physical and cognitive impairments. Although some members of the geriatric population may be healthy and robust, others may be frail or fully dependent on others for their daily activities including taking their medicine. Hence, there are diversity and personal differences in regard to their needs and acceptability of formulations and drug products.

A range of formulations exist in the market, some conventional and other novel dosage forms. Recently dosage forms considered as age-friendly, such as transdermal patches, have been authorised for treating age-related disease conditions. For example, the Exelon® (rivastigmine) patch for treating dementia and Lotrel® capsules as fixed dose combination of amlodipine and benazepril for the treatment of hypertension. However, the right formulation is not always prescribed for patients when taking into account any existing impairments. Similarly older patients and their carers may not be provided with full information in order to optimise the therapeutic effect. Some formulations may vary physically for the same drug (generics). For instance one might be white with a letter embossed and another might be plain with no embossing which could cause confusion by carers/patients. Therefore, patients need to be told about these differences to reassure them.

Packaging is an integral part of the drug product. The medicine pack is critical for the optimum use of the drug. So if older patients cannot open a medicine’s packaging, they simply cannot use it. Older people with manual dexterity problems and poor grip strength may struggle to open packs. Therefore, they may leave bottle caps off or use scissors to cut the blister packs. In particular child-proof bottles and ointment tubes with tight (or small) caps cause older people to struggle with taking their medicine. Therefore senior friendly packaging systems should be designed.

2.3. Multi-compartment compliance aids (MCAs)

When a patient is prescribed medication there is a general assumption that the full course as prescribed will be taken by the patient. Unfortunately, half of all medicines prescribed for patients with long-term conditions are not taken by the patient as intended by the prescriber (Haynes et al., 1996). This non-adherence can be intentional (e.g. related to the patient’s beliefs about the medicine) or unintentional (e.g. related to practicalities of medicine taking). Older people are prescribed multiple medicines and this coupled with age-related changes in pharmacokinetics and pharmacodynamics, makes them particularly susceptible to adverse drug events (Barber et al., 2009). Many have some degree of cognitive impairment that increases the risk of medication errors (Aldred et al., 2007). To tackle unintentional non-compliance, pharmacists in primary and secondary care currently use MCAs and automated pill dispensers for dispensing of solid-dosage forms (Chan et al., 2007).

Compliance aids aim to act as a reminder for patients to take their medication, enabling them to manage their own often complex and confusing drug regimens. They also act as a visual prompt for patients and carers indicating when the medication has been taken or as a prompt to take medication (Church and Smith, 2006).

The rationale with most multi-compartment compliance aid is that one compartment corresponds to a single administration time-point and all of the patient’s solid-dose medicines prescribed for that time-point are dispensed into that compartment by pharmacy staff. Where frequency of administration does not exceed four times a day, a 28 compartments multi-component compliance aid thus presents the patient with an exact seven-day dosing regimen for their solid-dose medication (Chan et al., 2007).

Recent publications and guidance by the Royal Pharmaceutical Society (RPS) (RPS, 2013; Fowells and Jankovic, 2013) have initiated
discussions centring around actual patient benefit (in terms of improvement of adherence and compliance) with the use of MCAs. Whilst this area is outside the scope of this communication further information are provided by Fowells and Jankovic (2013) and the RPS (2013).

3. Aim of the public engagement workshop

The main aim of the event was to provide a dynamic environment to voice older people’s and family carers’ perspective on development and use of medicine, exchange information and identify ways of improving current and future geriatric drug therapy.

4. Challenges reported by older people and carers

The challenges related to medicine use reported by the participants are classified as:

Physical difficulties

- visual problems – not able to read small print on bottles or in information leaflets;
- dexterity problems – not able to open packets, deal with gadgets, drop tablets;
- swallowing;
- tiredness/sleepiness – may lead to missing doses.

Cognitive difficulties

- confusion;
- memory problems – forgetting to take tablets at all, forgetting when just taken;
- comprehension – understanding of what medicines are for;
- stress due to disease symptoms – lack of effect of slow release.

Living difficulties

- living alone – no one to assist;
- carers requiring training in medicines use.

Medicine related difficulties

- usually polypharmacy – concerns about mixing tablets up when taking them as so similar and interactions of all meds;
- co-morbidities;
- medication reviews – lack of awareness of what they are entitled to from a pharmacist and/or general practitioner (GP);
- lack of advice from the pharmacist;
- doses in relation to weight/height of patient;
- confusion over names of medicines and generics;
- admissions to hospital – given all medications at once.

Other shared difficulties

- disposal of medicines;
- relationship with and role of the pharmacist;
- relationship with and role of the GP.

Although some issues raised during the public engagement workshop were not surprising to the researchers, older people also highlighted various aspects of medicine use which triggered various research ideas and highlighted the need to ensure that medicines were being used by older people/carers correctly. Some of the comments made by the participants are summarised below:

- GPs and pharmacists are seen as very busy professionals and some older people are concerned about wasting the time of healthcare specialists so they tend not to ask many questions even if they may have doubts about the appropriate use of their medicine;
- some of the participants have a belief that slow release tablets may not work when stress levels are high due to disease condition;
- sleepiness is seen as a problem which prevented them follow through their medication at home or taking their night-time dose;
- small tablets (described as tiny pills by the participants) are found to be so small that they can be lost between fingers, dropped or stick to containers and not noticed. Moreover counting the very small tablets was reported to be tricky if eyesight is poor;
- the similar appearance of generic formulations confuses older people. They cannot remember which medicine is which and what they do;
- carers admit forgetting to remove transdermal patches and replacing them with the new dose;
- although in principle colour coding is thought to be a way to cope with polypharmacy, patients would like to understand whether different colours related to medication type or different doses;
- participants struggle with reading punched expiry dates and prefer printed versions in a larger font;
- participants often break or drop tablets when they push them out of conventional blister packaging;
- interestingly older people would like to know whether they can take their medicine with food as well as with alcoholic drinks;
- dosette boxes are likely to be carried in the pocket and can open causing all tablets to mix together or move to the wrong compartments;
- compliance aids with a seven-day regimen is found to be helpful only in showing the time of administration, and not the way of administration. In addition compliance aids in box or blister form have a limited number of compartments which is not helpful as older people may need to take medicines more than four times a day;
- participants would like to see more detailed information on patient information leaflets including the effects on different ethnic groups/genders, side effects only seen in older people, any need for dose adjustment, possible interaction with other prescribed drugs or over the counter medicines;
- although some participants have no family support and struggle with taking medicine, there are older people with many carers using different ways to help them with their treatments;
- older people living without a family carer may travel to stay with family and may forget their medicine pack or change the administration routine;
- some participants find the process of hospital staff taking over home medication on admission difficult. Some of them feel forced to take all their medicines together (instead of set time points) so they hid some of them;
- some older people have problems in obtaining some medicines when travelling away from home as medicine was only supplied for one month. Travelling abroad is even more problematic, leading to older patients generating their own methods of dealing with medicines, such as splitting their many medicines into their luggage or carrying as much as possible so that they might be able to stay longer if it is difficult to return home as planned;
- older people feel isolated in the GP/pharmacist/patient triangle receiving limited guidance in taking their medicine;
- most of the participants forget to take their medicine at some point. It is important for them to know whether they should take the medicine immediately once they remembered or wait until the next morning to take the medicine;
• older people feel that the information about medicine use should be relayed gradually so that they do not feel anxious;
• older people express frustration that they often do not understand the leaflet information due to the medical and technical language.

5. Resilience strategies reported by older people and carers

The participants of the workshop, who were all actively involved in their own therapies, shared their ideas for solutions to the medicine-related problems raised. Older people would like to be able to select from different formulations and they would like more research to be conducted towards developing various dosage forms for drugs. The participants thought liquid medicines with various textures would be helpful to select the medicine easier to take. The participants also proposed standardising the colour coding to provide consistent information on indication, dosage, interaction with other drugs, administration time and condition. A logbook with list of medications was suggested for the patient to carry with them at all times. They recommended placing codes/tags to scan using smart phones to get information about dosage, administration time, side effects and so on. A legible font size is very important both on medicine and compliance aids for older people with visual impairments. It is not easy for older people to change their habits, for example, of storing medicines by the kettle or in their handbag. The participants would like researchers to develop a personalised system, ‘medicine pot’ for storing various types of formulations all together at home. They suggested having a waterproof card which they could carry on them which would include all the information about their medicine use. Training of patients and carers was also said to be paramount for them. Older people prioritised the training support for family carers as this gives them a sense of security knowing someone close to them is able to administer their medicine.

6. Workshop learning outcomes

A brief overview of outcomes on medicine use, formulations, administration devices and MCAs are discussed in this section.

7. Medicine use

Older people were grateful that medication is available for their conditions and that information/guidance can be received from healthcare specialists. However, patients build their own strategies in managing their therapy over time and they highlighted the need for continuity of relationships between consultant, general practitioner, patient and pharmacist to establish consistent information flow between these stakeholders. Participants declared that communication with a different pharmacist prevents the appropriate follow-up of the management of their medicines. One of the problems is the fact that not all healthcare staff work full-time and/or is not permanently based at surgeries/pharmacies. Participants made a comment about being seen by different people who may prescribe completely different medications increasing the risk of incompatibility between the medicines being used. A similar point was made in regard to general practitioner’s perspectives on geriatric conditions. Despite the prevalence of geriatric diseases, general practitioners may not often see co-morbidities. Polypharmacy can lead to drug interactions and side effects which GPs may not recognise as such and instead prescribe another drug to deal with it rather than just lower dose or discontinuing the drug. In this respect, the need for monitoring older patients’ medicine use was also mentioned. This led to the medicine use review (MUR) service being an important discussion point of the workshop, especially as many patients perceive polypharmacy as “taking too many drugs”. A MUR is a free and private consultation offered by pharmacies in the UK to explain to patients about their prescription, the appropriate use of their medicine and solutions for medicine use related problems. It was observed that the majority of older patients were not aware of the MUR service although they are the patient population group that should be receiving this service due to the increased likelihood of them taking more than one prescription medicine. The appropriateness of the frequency, provider and setting of MUR was discussed. Raising awareness on MUR and the NMS were well-received as older people would like to have this information and make informed decisions about their medicine. Participants further commented about the need for guidance on taking common over the counter medicines alongside their prescription medicines. They also raised the issue of whether or not a carer could be present at the MUR.

8. Formulations

Older patients shared their opinions on both traditional and advanced drug formulations. In particular they felt that they had a lack of knowledge in relation to how extended release tablets work. They believed slow release formulations were inadequate when a quick drug action was required, for example, in the case of Parkinson’s patients. This example also highlights the importance of adequate explanation of the pharmaceutical terms used and the drug mechanisms to patients.

9. Multi-compartment compliance aids (MCAs)

MCAs are widely available to improve patient outcomes in terms of medicine management. However, participants felt that these aids may actually hinder compliance. This is because all contextual information on the appropriate use of their medicine is lost when they receive them in the compliance aid systems. They often forget which drug is used for treating which condition. Some of them have access to sealed and blistered systems but the majority were using dosette boxes which could lead to possible errors in taking medicine.

The automated medicine dispensers such as the carousel system were seen to be potentially useful. However, participants were concerned about having to deal with the medicines if the system broke down.

Participants found it difficult to take many medicines at the appropriate time. They shared the difficulties they had in remembering which pill does what, especially when they are loaded into pill organisers and taken out from their containers. Possible errors such as loss of patient information leaflets and consecutive use of incompatible medicines were mentioned. They found that loading medicines into a dosette box was problematic as most of the medicines look similar in shape, size and colour. Due to the difficulty in differentiating drugs from each other, they tend to take multiple medicines at one go around meal time even though some of them should be taken before meals. There was an interesting suggestion to have quick response (QR) codes on medicines which could be scanned to show instructions for use, e.g. with food during lunch time. A smartphone application scanning these codes may also help patients and carers to check what medication it is and to make a decision on what to do with it. QR codes may be designed to show more information after scanning, with dosage details, drug interactions and side effects. It would also be useful for care agency workers and pharmacists during a review or when patients bring pills to be identified. Both older patients and carers would like to be able to easily check the purpose of using their medicine. However, they found confusing to match the medicine in the compliance
aid with the patient information leaflet which had been provided separately. Some participants suggested putting a standardised set of symbols on the medicine to represent the function and target condition of the medicine. Additionally colour-coding of pills was suggested to help to distinguish different types of medicine.

10. Conclusion

Older people should take part in shaping priorities which affect their well-being. The public engagement workshop was a great platform to listen to older people and to understand common errors and problems experienced by them and the coping strategies that they develop. Older people and family carers shared their valuable experiences and suggested solutions to overcome some of the challenges related to medicine use. Patients’ knowledge about their illnesses is deep and wide. Patient engagement is very helpful in developing valid research questions and strategies for appropriate medicine use. Including older people in such discussions is vital for translating pharmaceutical studies into patient centric products.

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