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1 **Using public engagement and consultation to inform the development of ageing- and**
2 **dementia-friendly pharmacies - Innovative Practice**

3 **Abstract**

4

5 This study explored public perceptions about the importance of, and how to create, ageing-
6 and dementia-friendly pharmacists and pharmacies. In September 2016, four focus groups
7 (45 minutes each) were conducted with sixteen participants who represented organisations,
8 groups or forums working with and/or for older people and people with dementia in
9 Greater London. Discussions were recorded via hand-written notes and thematically
10 analysed. Participants confirmed the importance of pharmacists and pharmacies being
11 ageing- and dementia-friendly and described variability in whether this is currently the case.
12 Suggested strategies for improvement included targeting communication, pharmacist
13 leadership and shop layout.

14

15 **Word count**
16 1,765
17 **Key words**
18 Ageing, dementia, geriatric medicine, medication, pharmacy

19 **Running title**
20 Ageing- and dementia-friendly pharmacy services

21 **Introduction**

22

23 Consumers, policy makers and researchers world-wide have become increasingly interested
24 in the concept and development of dementia-friendly communities (Alzheimer's Disease

25 International). A dementia-friendly community is defined by the Alzheimer's Society as
26 *'supportive and inclusive of people affected by dementia'* (Alzheimer's Society) and by
27 Alzheimer's Australia as *'a place where people living with dementia are supported to live a*
28 *high quality of life with meaning, purpose and value'* (Alzheimer's Australia, 2017). A priority
29 area in creating dementia-friendly communities is access to appropriate healthcare services,
30 to support people with dementia to live at home for as long as possible (Alzheimer's
31 Australia, 2017).
32
33 Pharmacies are important places that people with dementia visit (Brorsson, Ohman,
34 Lundberg, & Nygard, 2011). People with dementia are prescribed multiple medications
35 (Schubert et al., 2006) and they consider pharmacists as crucial to their medication
36 management team (While, Duane, Beanland, & Koch, 2012). As a result, pharmacies should
37 be ageing- and dementia-friendly (Bennett, 2015). The Alzheimer's Society (Alzheimer's
38 Society, 2015) and Alzheimer's Australia (Alzheimer's Australia, 2017) have developed
39 toolkits to support businesses in the pursuit of becoming dementia-friendly, with
40 suggestions including: pharmacists should identify specific medication needs of local people
41 with dementia and their carers, to ensure tailored, person-centred pharmacy services; staff
42 should be trained in dementia-appropriate communication; and the pharmacy workplace
43 environment should be assessed for adequate signage, lighting, colour contrast, labelling
44 and quiet areas (Alzheimer's Australia, 2017; Alzheimer's Society, 2015; Stafford, 2015).
45
46 This study aimed to explore the perceptions of individuals who represent organisations that
47 work with and/or for older people and people with dementia, regarding the importance of
48 ageing- and dementia-friendly pharmacists and pharmacies, and how they can be created.

Methods

In September 2016, JG-T presented a public seminar at the Age UK London's offices concerning her Australian ageing- and dementia-related research. All individuals on the Age UK London's offices electronic mailing list were invited to attend. These individuals represented at least 500 organisations, ranging from small, local clubs to large forums with over 1000 members, working with and/or for older people and people with dementia in Greater London. The first 20 interested individuals were registered to attend. Immediately after the public seminar, JG-T invited all attendees to participate in a focus group. A study explanatory statement was provided and a signed consent form was required. Seminar attendees were invited to participate in this study as their work roles increased the likelihood that they could knowledgeably contribute to the study.

It was anticipated that all 20 public seminar attendees would participate in the study, leading to a total of four focus groups with five participants each. The total number and size of focus groups was chosen to ensure all relevant issues would be identified without new ideas emerging (Smith, 2002) and that all participants could contribute to discussions (Krueger, 1994; Smith, 2002). Each focus group was moderated by one of four facilitators (including JG-T). This allowed multiple focus groups to be conducted simultaneously, after the public seminar had concluded, at the Age UK London's offices. All facilitators had experience undertaking qualitative research, were appropriately skilled to guide discussions without influencing them and to ensure equal participant contributions, and three of them were pharmacists (Patton, 1990).

To maintain anonymity, and as per the study ethical approval, participant names were not used during discussions, audio-recording was not possible and identifying information could not be recorded. Each facilitator used hand-written notes to record the main focus group discussion points and participants had the opportunity to assist the facilitator in ensuring that their contributions were accurately recorded. This methodology has been recommended in circumstances where audio-recording is not possible (Kitzinger, 1995). This study followed similar, successful methodology where public engagement has informed priorities in health and social care research and practice (Alsaeed et al., 2016; Poland et al., 2014).

An open-ended, semi-structured question guide (McNeill & Chapman, 2005) was developed by JG-T (Table 1) to allow participants to raise new ideas or issues that they believed were important, which focus group facilitators could further explore by asking additional questions (Smith, 2002). Communicative validity was assessed in this study by comparing study findings with existing dementia-friendly community guidelines (Alzheimer's Australia, 2017; Alzheimer’s Society, 2015; Smith, 2002).

Table 1. Semi-structured question guide

Number	Question
1	What makes a health care environment/health care professional ageing- or dementia-friendly?
2	How important is it that pharmacies/pharmacists are ageing- and dementia-

	friendly?
3	Do you perceive that pharmacies/pharmacists are ageing- and dementia-friendly currently (and describe how they are or are not)?
4	What are your recommendations to make pharmacies/pharmacists more ageing- and dementia-friendly?
5	How should we be educating our pharmacy students/health care professional students to be more ageing- and dementia-friendly?

92

93 *Ethical approval*

94

95 As JG-T was based at Monash University (Australia), ethical approval was obtained from the
96 Monash University Human Research Ethics Committee (Project Number: 0742). This ethical
97 approval allowed JG-T to conduct the study in the UK.

98

99 *Data analysis*

100

101 Data were analysed using a thematic approach, which involved familiarisation with the raw
102 data, identification of key themes as they emerged, defining and naming themes, formation
103 of an initial coding frame, and indexation of the data to that coding frame (Pope, Ziebland,
104 & Mays, 2000). The coding frame was discussed among all four focus group facilitators to
105 ensure the validity and credibility of data analysis and to clarify discrepancies.

106

107 **Results**

108

109 Four focus groups, of approximately 45 minute duration, were conducted with a total of 16
110 participants (only 16 of the 20 public seminar registrants actually attended the public
111 seminar). The seven male and nine female participants were representatives of
112 organisations, groups or forums working with and/or for older people and people with
113 dementia in Greater London. Participant work roles ranged from positions of leadership to
114 lay members and volunteers. Many participants were aged older than 55 years and used
115 their and their members' personal experiences to inform discussions. According to the
116 ethical approval of the study, specific participant characteristics were not recorded.
117 Identified themes are presented below in italics.
118
119 *The importance of ageing- and dementia-friendly pharmacists and pharmacies.*
120
121 Participants explained that as the population is ageing and the number of people with
122 dementia is increasing, there is an increase in healthcare being provided in the community
123 setting, and pharmacies are community-based healthcare destinations that are accessible to
124 older people and people with dementia. However, they explained that there does not
125 appear to be a satisfactory ageing- and dementia-friendly standard being adhered to by
126 pharmacists and pharmacies. Participants mentioned that it could be more difficult for
127 pharmacies to be ageing- and dementia-friendly if they were part of large organisations,
128 compared to smaller, independent pharmacies, where staff could be more familiar with the
129 community they serviced.
130
131 *Strategies to improve how ageing- and dementia-friendly pharmacists are.*
132

133 Participants suggested that when communicating, pharmacists should: allow people with
134 dementia adequate time to communicate without feeling rushed; use eye contact; be calm,
135 patient and respectful; physically approach patients from behind pharmacy barriers; and
136 consider writing important information down for the patient where necessary. Participants
137 suggested that pharmacists could ask general practitioners to help them identify patients
138 with dementia, so that a dementia register could be developed and more individualised
139 services provided. However, pharmacists would need to be aware of the risk of stereotyping
140 or labelling people with dementia. It was suggested that pharmacists could also adopt a
141 leadership role in providing ageing- and dementia-friendly services and encourage other
142 pharmacists to also take on this role. When referring to healthcare professionals in general,
143 participants suggested that they should adopt a positive ageing- and dementia-friendly
144 attitude and that dementia-friendly terminology should be used when communicating
145 about dementia (e.g. 'living', compared to 'suffering' from dementia).
146
147 *Strategies to improve how ageing- and dementia-friendly pharmacies are.*
148
149 Participants recommended that: pharmacies are easily identifiable and accessible if they are
150 located within large shops; signage should be clear and limited in number; there should be
151 seating, a private consultation room and a hearing loop system; door mats should not be
152 black; and a clear and concise list of what pharmacies do or do not do should be present, as
153 well as information regarding where older people can access healthcare services. It was
154 recommended that pharmacies adopt ageing- and dementia-friendly standards, which are
155 developed in conjunction with people with dementia and their carers. Additionally,
156 pharmacies should be regularly assessed for dementia-friendliness (e.g. using mystery

157 shoppers) and provided with a dementia-friendly rating or clear signage that identifies them
158 as dementia-friendly.
159
160 *Strategies to improve how ageing- and dementia-friendly healthcare professional students*
161 *are.*
162
163 Participants recommended that students should undertake work experience in different
164 settings (care homes, hospitals, pharmacies, dementia cafes, memory clinics, day care
165 centres) where they may encounter older people and people with dementia. Additionally,
166 students could be asked to explore the experiences they've had with their grandparents or
167 become friends with older people. Participants explained that the ageing- and dementia-
168 friendly theme should be incorporated throughout all years of the educational program, it
169 should be compulsory for students to attend ageing- and dementia-related topics, and
170 relevant topics could be taught by older people and people with dementia. Participants felt
171 that students should understand that older people and people with dementia differ in terms
172 of their characteristics and needs and that ageing does not always lead to cognitive
173 impairment or dementia.
174
175 **Conclusion**
176
177 This study has provided important insight into public perception of the importance of
178 developing community pharmacies as dementia-friendly environments. Participant
179 suggestions of how to develop dementia-friendly pharmacies were similar to those in
180 Alzheimer's Society and Alzheimer's Australia guidelines (Alzheimer's Australia, 2017;

181 Alzheimer's Society, 2015) including, clear signage, considering the input of people with
182 dementia when designing dementia-friendly environments, and using dementia appropriate
183 language (Swaffer, 2014). With regards to the suggestion of a dementia register, increasing
184 pharmacist awareness of patients with dementia may instead be addressed by the current
185 National Health Service (NHS) initiative to allow community pharmacists to view Summary
186 Care Records (SCR) (NHS Digital, 2017a, 2017b). These patient-specific electronic records are
187 created from general practitioner medical records, must contain certain patient information
188 (e.g. current medications), and may contain other information if the patient wishes (e.g.
189 chronic medical conditions, such as dementia) (NHS Digital, 2017a, 2017b). Pharmacists can
190 view SCR if they are involved in the patient's care and have their consent (NHS Digital,
191 2017a, 2017b). Pharmacist-accessible SCR could address potential issues associated with
192 developing a pharmacy-based dementia register, such as not having a regular pharmacist to
193 whom details of the person with dementia could be sent, the need for a general practitioner
194 to obtain consent before disclosing medical details about a specific patient, and the
195 difficulties associated with establishing comprehensive data protection policies and
196 practices. In terms of policy, practice and research implications: the Alzheimer's Society and
197 Alzheimer's Australia should collaborate with pharmacy organisations like the Royal
198 Pharmaceutical Society of Great Britain and Pharmaceutical Society of Australia, to
199 determine how best to support the implementation of available guidelines (Alzheimer's
200 Australia, 2017; Alzheimer's Society, 2015); pharmacists should explore local logistical,
201 organisational, financial and personal barriers and facilitators to guideline implementation;
202 and future research should comprehensively explore whether ageing- and dementia-friendly
203 strategies are currently being implemented into pharmacies.
204

205 **Declaration of Conflicting Interests**

206 None Declared

207 **Supplementary Materials**

208 Data available upon request

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