

# Co-developing end-of-life resources *an equal and reciprocal relationship*

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## SEED

The **SEED** programme - **S**upporting **E**xcellence in **E**nd of life care in **D**ementia

Funded by the National Institute for Health Research (NIHR)  
Programme Grant (Applied Research).

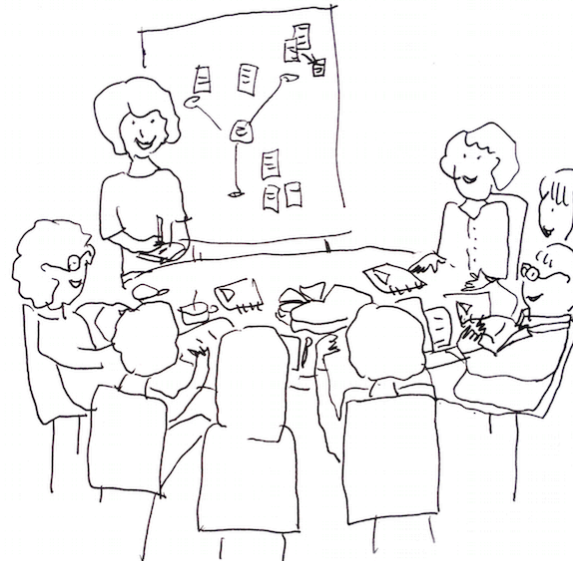
PI Prof Louise Robinson, Newcastle University.

<https://research.ncl.ac.uk/seed/>



## Focus of presentation

**How do we involve people with dementia, their families and carers, in co-designing a resource for difficult conversations and decisions about key end-of-life plans?**



## The Design Challenge

- a sensitive approach recognizing not only disability but also empowering and supporting capability
- some Patient and Public Involvement (PPI) models can be too narrow, indeed tokenistic, not acknowledging equality and diversity issues <sup>1</sup>
- shifting PPI thinking from 'doing to', and 'doing for' to '**doing with**' people <sup>2</sup>

1. Ocloo J, Matthews R. (2016). From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Qual Saf.* 25 (8).

2. New Economics Foundation (2014). *Co-producing wellbeing. Why it matters and how to do it.* Available at: <https://prezi.com/eitdkealy8t/co-production-theory-and-practice/>

## Nature of co-design approach taken

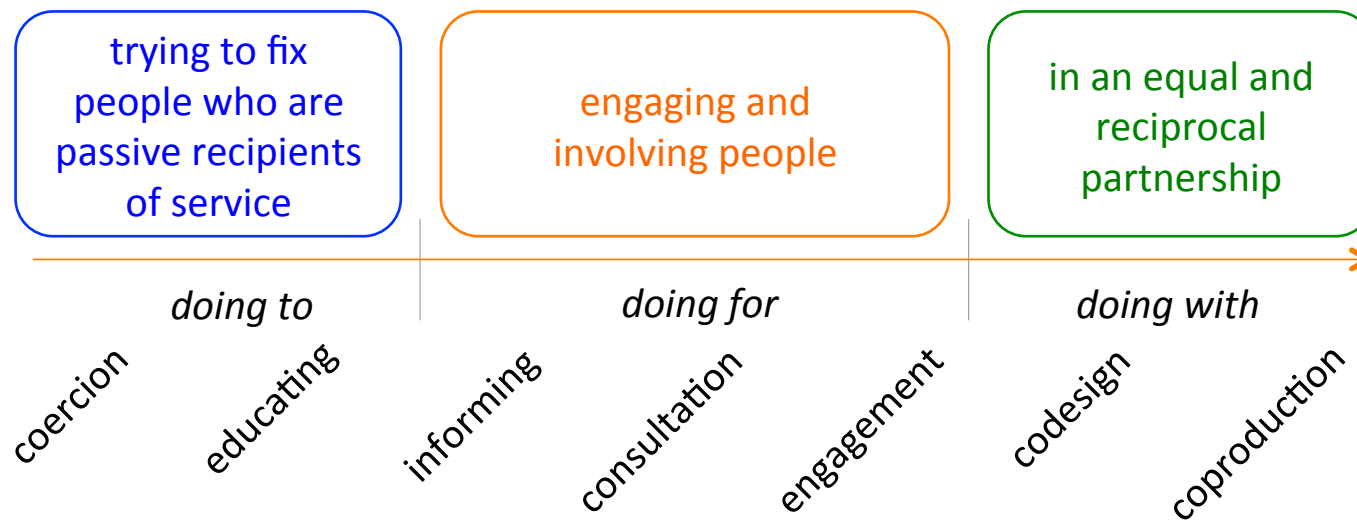


Diagram derived from: New Economics Foundation (2014). Co-producing wellbeing. Why it matters and how to do it. Available at: <https://prezi.com/eitdkealy8t/co-production-theory-and-practice/>



## Why involve Design researchers from the Glasgow School of Art?

We are experienced in:

- Inter-disciplinary team-working within healthcare
- ‘Inclusive Design’
  - Participative co-development of tools and interventions
  - ‘convivial’ workshop design
- Mock-ups and prototypes as a means of hypothesising, questioning and acquiring data
- Visualisation of data

## Design methods

**Design researchers** joined the more traditional specialisms in the research team ...

*dementia*

*palliative*

*nursing care*

**... introducing methods and tools to involve all the key stakeholders i.e.,**

*people with dementia*

*family carers*

*healthcare teams*

*nurse specialists*

## Findings from SEED qualitative research - work stream 2

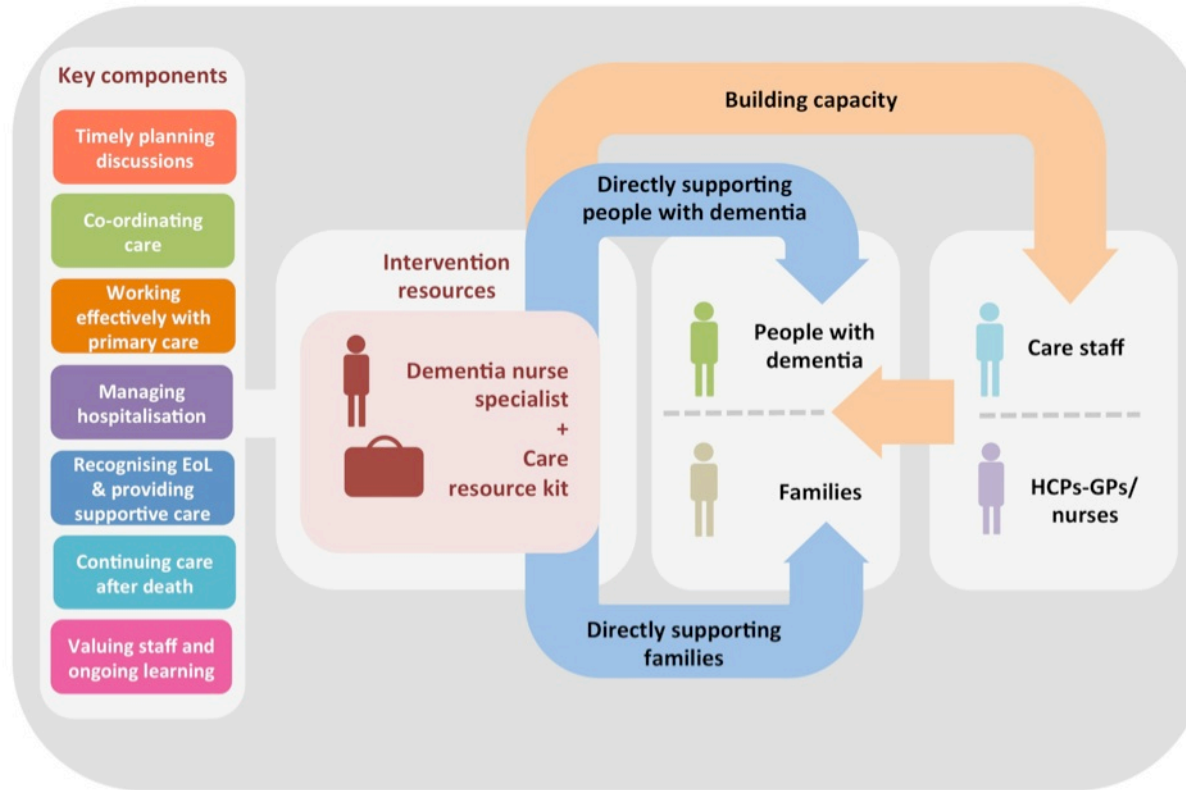
Findings indicated 7 key factors influence end-of-life care in dementia <sup>1</sup>:

1. Timely planning discussions
2. Recognition of end of life and provision of supportive care
3. Co-ordination of care
4. Effective working relationships with primary care
5. Managing hospitalisation
6. Continuing care after death
7. Valuing staff & on-going learning

1. Bamford, C., Poole, M., Lee, R., McLellan, E., Exley, C. & Robinson, L. (2017). Improving End-of-life Care in Dementia: Key Areas for Improvement. *Innovation in Aging*, 1(suppl\_1), 266-266.



## The SEED Intervention



An intervention to increase the chances of a good death for people with dementia

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Resource to support **timely planning discussions**

**Means**

**Care Plan Guide (CPG)**

**Purpose**

To **enable** and **encourage discussion** of **key plans** and **joint decision-making** between people with dementia and their families and carers.

## Resource to support **timely planning discussions**

### **Key plans**

- 1) lasting power of attorney (health & welfare; and property & finance)
- 2) advance statement
- 3) advance decision to refuse treatment (including non-resuscitation)
- 4) making a will
- 5) funeral planning



Resource to support **timely planning discussions**

**Initial specification for Care Plan Guide**

- entry level explanations
- user friendly language avoiding legalistic jargon
- all plan details in one document
- record of progress, decisions, location of actual documents
- freely available
- downloadable

## Design-friendly / accessibility design issues

For example

*app interface* <sup>1, 2</sup>

*language* <sup>3</sup>

*legible print* <sup>4</sup>



1 Dementia Engagement and Empowerment Project (2013) *Guide: Creating websites for people with dementia*.

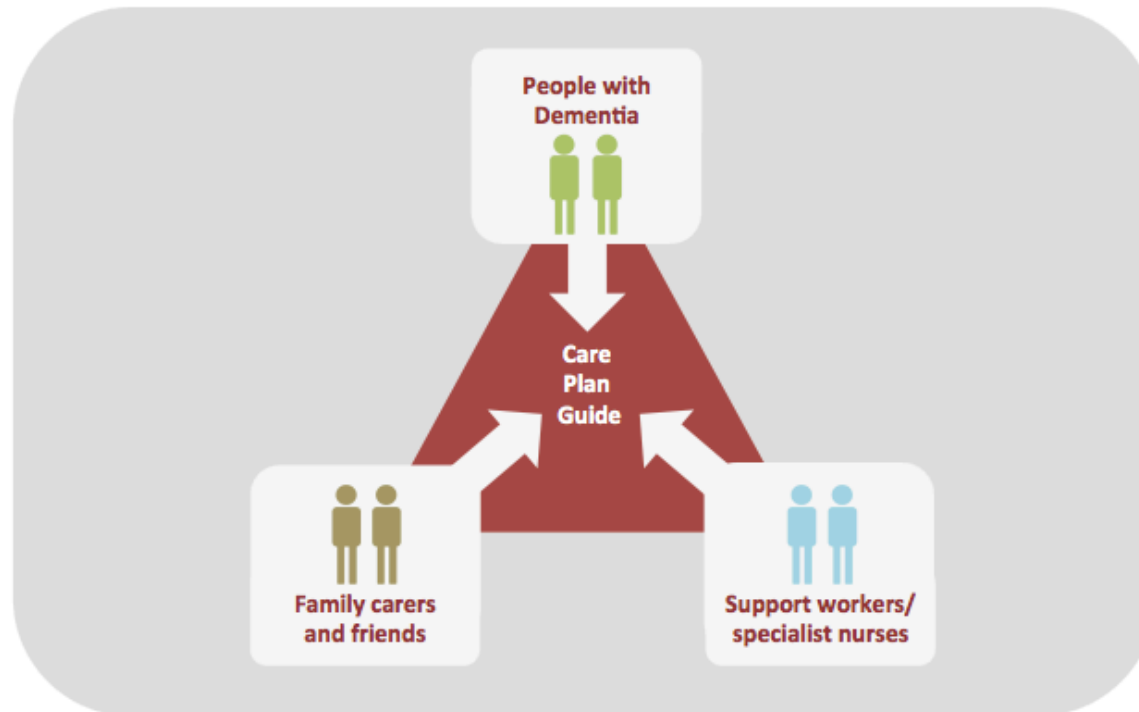
2. Joddrell, P. & Astell, A. (2016) Studies involving people with dementia and touchscreen technology: A literature review. *JMIR Rehabilitation Assistive Technologies*, 3(2), e10.

3. Dementia Engagement and Empowerment Project (2013) *Writing dementia-friendly information*.

4. Knowles, D. (2014) *Dementia Friendly Print*

## Co-design through stakeholder workshops

As the use of the CPG would involve all stakeholder groups in discussions at some point, its development requires input from each of these groups.



## Co-design through stakeholder workshops

5 workshops: 2 x PPI advisory group + 3 x stakeholders



Specific questions discussed in the workshops included

- The concept of the CPG
- Content
- Format
- Language
- Medium
- Design
- Title
- Other comments



## Participants

### *Workshop 1*

*PPI Advisory Group; 9 participants*

### **Workshop 2: Professionals**

9 participants: 8 support workers and 1 registered nurse

### **Workshop 3: People with Dementia, Family Carers & OTs**

7 participants: 2 people with dementia, 3 family carers and 2 occupational therapists

### **Workshop 4: People with Dementia & Family Carers**

4 participants: 2 family carers and 2 people with dementia

### *Workshop 5*

*PPI Advisory Group; 8 participants*

## Recruitment

### Workshops 1 & 5: PPI Advisory Group

- The priority-setting group from the **Alzheimer Society's Research Network** contribute to a **Patient/Public Advisory Group** (PPAB); additional network members will be recruited to ensure a membership of 8-10 members throughout the programme

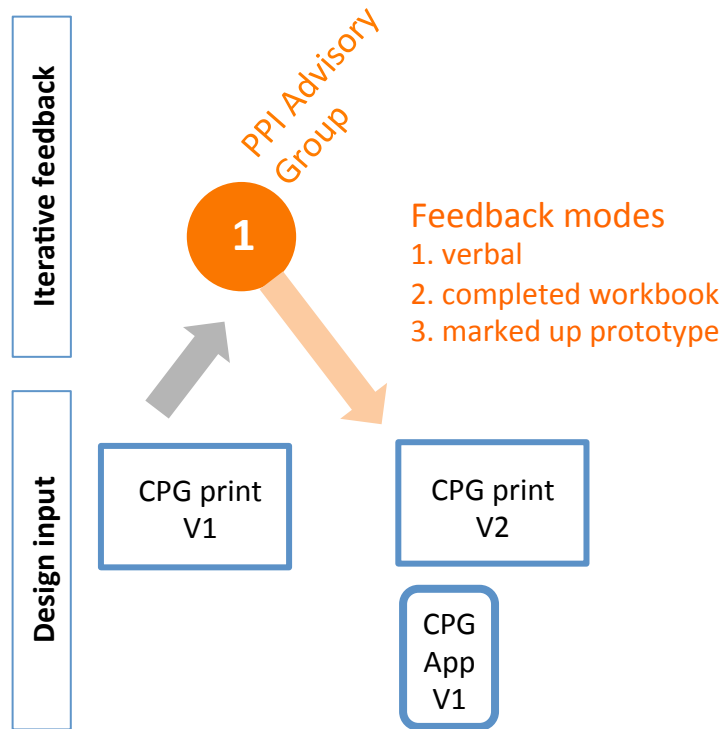
### Workshop 2: Recruitment of Professionals

- Recruited from a specially designed **community complex with 6 supported households aiming to create a family atmosphere for older people requiring full-time care**, including those with dementia.

### Workshop 3 & 4: Recruitment of families and people with dementia

- Invited to participate through the support of the project manager at **Alzheimer Scotland for Dementia Circle**, who acted as a 'gate-keeper' to identify potential participants and introduce the researcher to the groups.

## The co-design process for CPG booklet and app



# The Prototypes *print version – sample pages*

**Living for today,  
planning for tomorrow**

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A guide to facilitate discussions between people living with dementia and their families

Your name \_\_\_\_\_

The Glasgow School of Art ASM/SN\_V6\_12/06/2017

My advance care plan - My lasting power of attorney 8

**Important to plan: lasting power of attorney (LPA)**

Use this to help decide the discussions you need to have

	Property & finance	Health & welfare
Is this something there is important and want to do?		
Which family members or professionals would be able to take on the responsibility?		
What are the first steps?		

My will 10

**My will**

**The purpose of a will**  
Making a will can give you control over how your property and belongings are distributed, secure your funeral arrangements, and ensure good tax planning at the end of life.

**Advantages of making a will**  
If you die without making a will, your money and belongings will be divided according to legal rules. This may not be what you want or expect, for example, if you are married with children, not everything will automatically go to your spouse.

If you die without a will, sorting out your affairs after your death will probably be more time consuming and costly.

If you care for someone else, you can make sure that provision is made for care to continue after your death.

**How to make a will?**  
You can buy kits or download them from the internet. A solicitor or family lawyer may draw up a will for a fixed fee. Every year there is more a will, most often solicitors will draw up a will for a donation to charity.

**In what circumstances would my will need to be reviewed or updated?**  
When family circumstances change through divorce, separation, death or birth or if your financial situation changes (e.g. you win the lottery).

**Legal issues and requirements**  
To make a will you need to have mental capacity and the will needs to be signed and witnessed.

My personal record overview 16

	When	Complete	Review	Review
<b>My advance care plan</b>	When <input type="checkbox"/>	Complete <input type="checkbox"/>	Review <input type="checkbox"/>	Review <input type="checkbox"/>
<b>My will</b>	When <input type="checkbox"/>	Complete <input type="checkbox"/>	Review <input type="checkbox"/>	Review <input type="checkbox"/>
<b>My funeral plan</b>	When <input type="checkbox"/>	Complete <input type="checkbox"/>	Review <input type="checkbox"/>	Review <input type="checkbox"/>

Check you have completed you can print  or print by email  and share your personal record. Thank you!

## The Prototypes *print version – sample pages*

### Important to plan: lasting power of attorney (LPA)

Use this to help decide the discussions you need to have

	Property & finance	Heath & welfare
Is this something I think is important and want to do?		
Which family members or professionals would be able to take on the responsibility?		
What are the first steps?		

## The Prototypes *print version* – sample pages

My advance care plan - My lasting power of attorney 9

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**Use this to check that all important matters have been completed**

	Property & finance	Heath & welfare
LPA completed?	Yes <input type="radio"/> No <input type="radio"/> When <input type="text" value="/ /"/> <input type="calendar"/>	Yes <input type="radio"/> No <input type="radio"/> When <input type="text" value="/ /"/> <input type="calendar"/>
LPA registered?	Yes <input type="radio"/> No <input type="radio"/> When <input type="text" value="/ /"/> <input type="calendar"/>	Yes <input type="radio"/> No <input type="radio"/> When <input type="text" value="/ /"/> <input type="calendar"/>
Name(s) of 'attorneys'	<input type="text"/>	<input type="text"/>

## **The Prototypes *print version* – *sample information headings***

### **Lasting power of attorney (LPA) (*health and welfare*)**

The purpose of a health and welfare LPA

How to choose an attorney for health & welfare

How to go about making an LPA

In what circumstances would the LPA need to be reviewed or updated?

Where can I get more information?

## The Prototypes *print version – sample questions*

### **Lasting power of attorney (LPA) (*property & finance / health and welfare*)**

Is this something I think is important and want to do?

Which family members or professionals would be able to take on the responsibility?

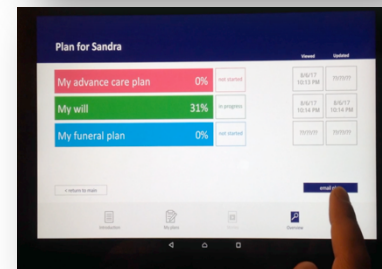
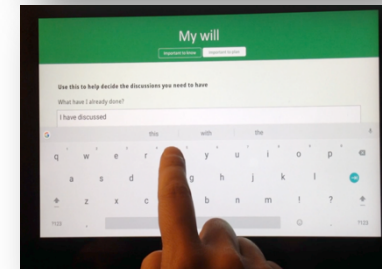
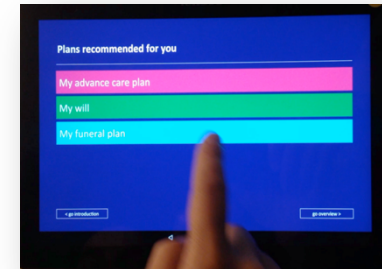
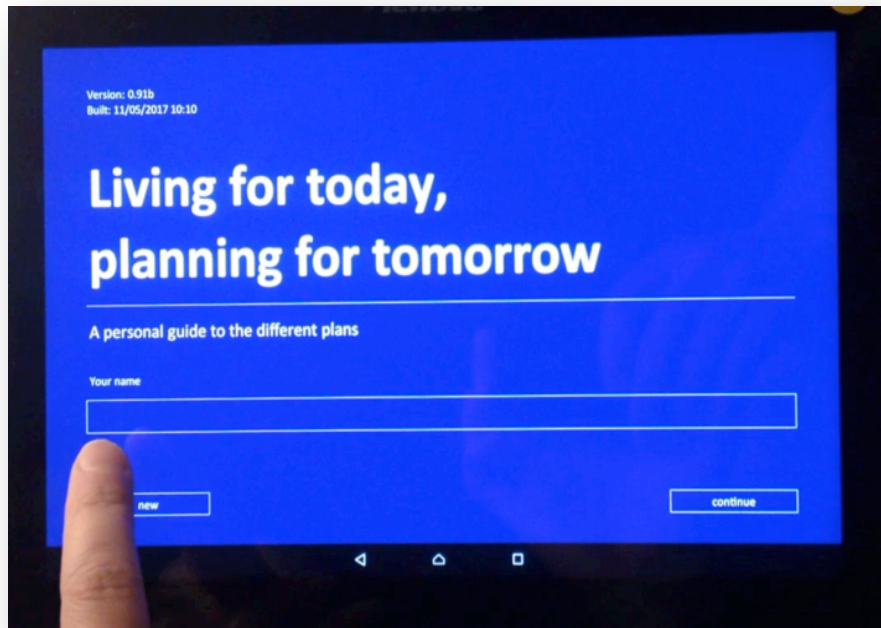
*LPA completed: no / yes / date ?*

*LPA registered: no / yes / date ?*

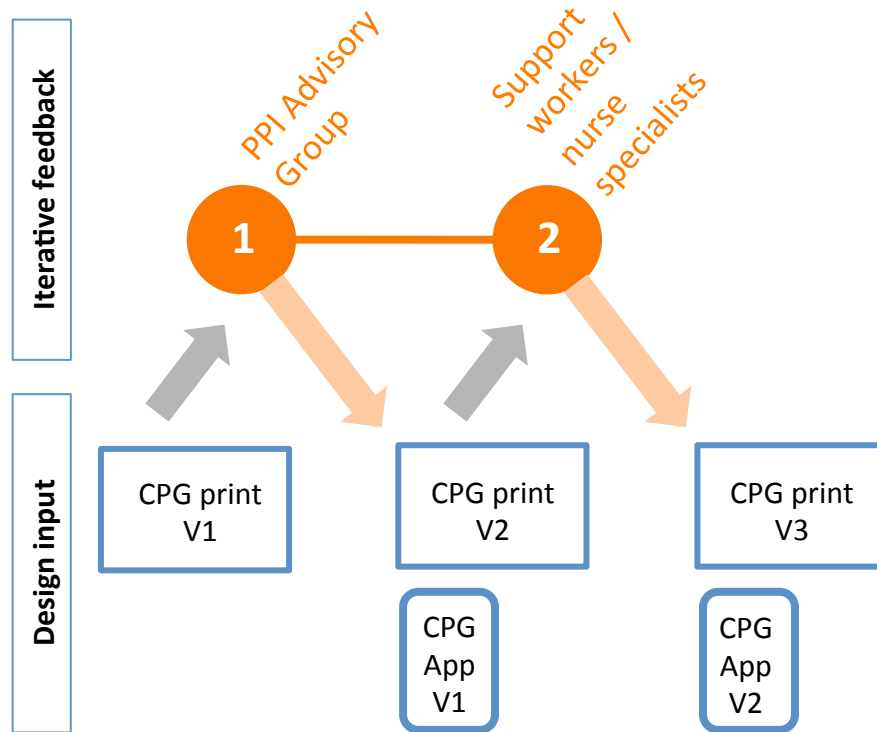
*Names of 'attorney'?*



# The Prototypes app version – sample interactive screens

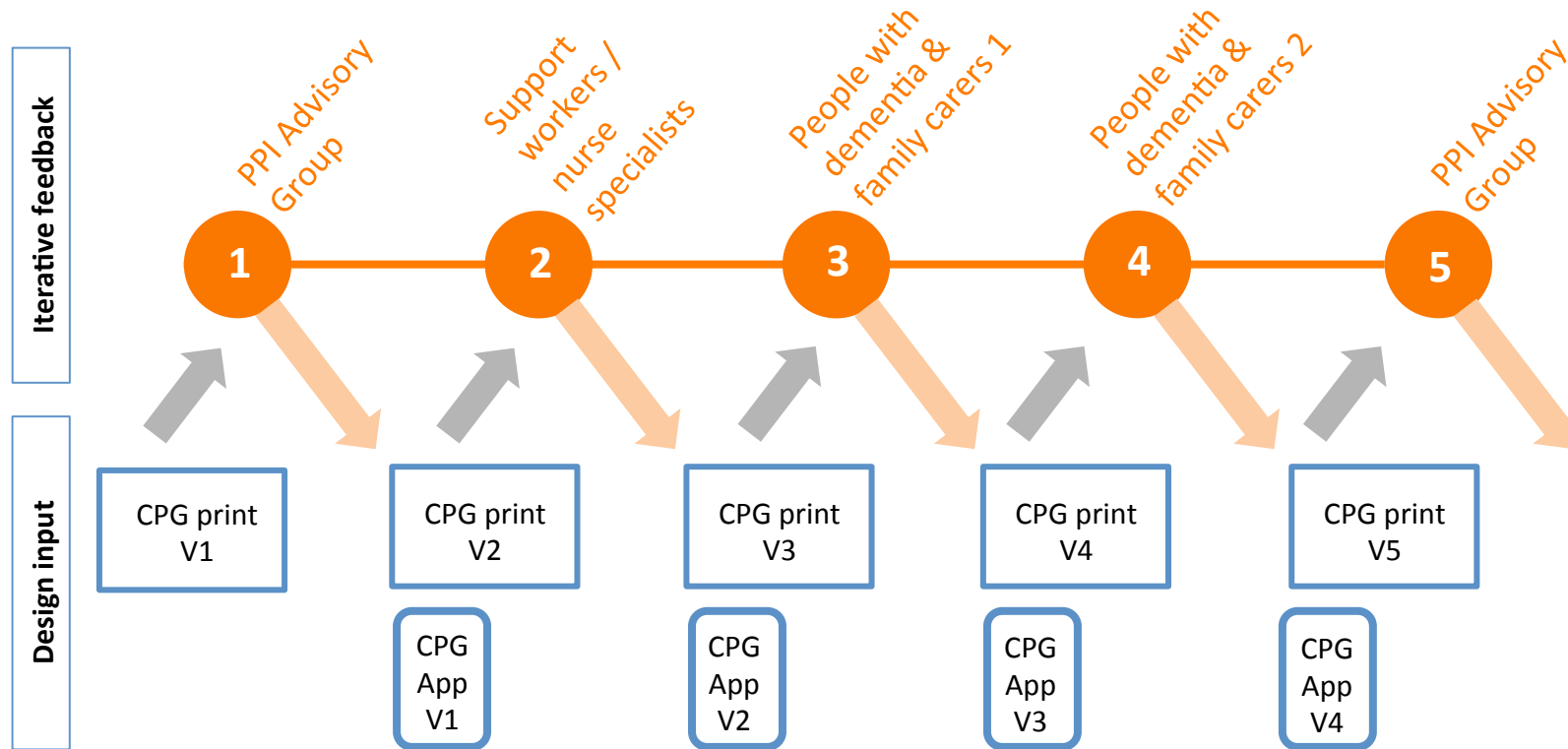


## The co-design process for CPG booklet and app



Iterative development: prototype paper & app versions of Care Plan Guide (CPG)

## The co-design process for CPG booklet and app



Iterative development: prototype paper & app versions of Care Plan Guide (CPG)

## PwD and family carers' feedback

*Samples from prototype mark-up, workbooks and group discussions*

*'What is the first step I can take? – not clear what does it means'*

*'Not using acronyms (e.g. AS) you need to write all name'*

### Advantages

*'Colours make this easy to read'*

*'Is handy, easy, accessible'*

*'Everything is in one place'*

*'Save paper work'*

*'After this, I would prefer the app'*

### Disadvantages

*'We have to be knowledgeable to find this'*

*'Functionality, make it work'*

*'Apps should have a diagram [to explain]  
how to use it.'*

## Findings 1

Overall, participants indicated that the CPG, as a **general concept, would not only positively address the intended purpose of facilitating timely planning discussions between people with dementia and their families and carers** but would also be **helpful for many other individuals wishing to have these types of difficult timely planning discussions.**

## Findings 2

The CPG structure, with its overview, general introduction to each plan, detail and links to further information, with **all information kept in a single place together with the record of progress and decisions against each plan** were all seen as helpful.

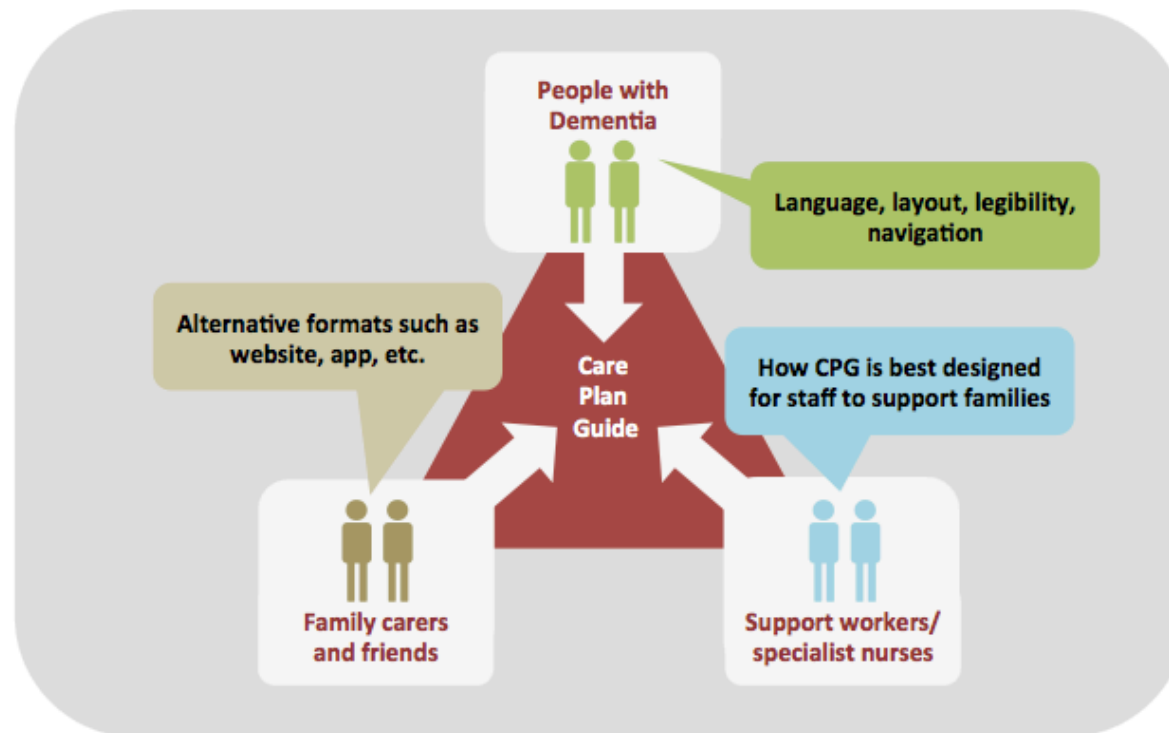
Suggested improvements: **navigation; colour to differentiate different sections; font size; and arrangement and amount of text**, were embodied in further iterations of the CPG (both paper and app versions) for subsequent workshops.

The initial use of **acronyms** and **formal legal language** were regarded as unhelpful and later revised.

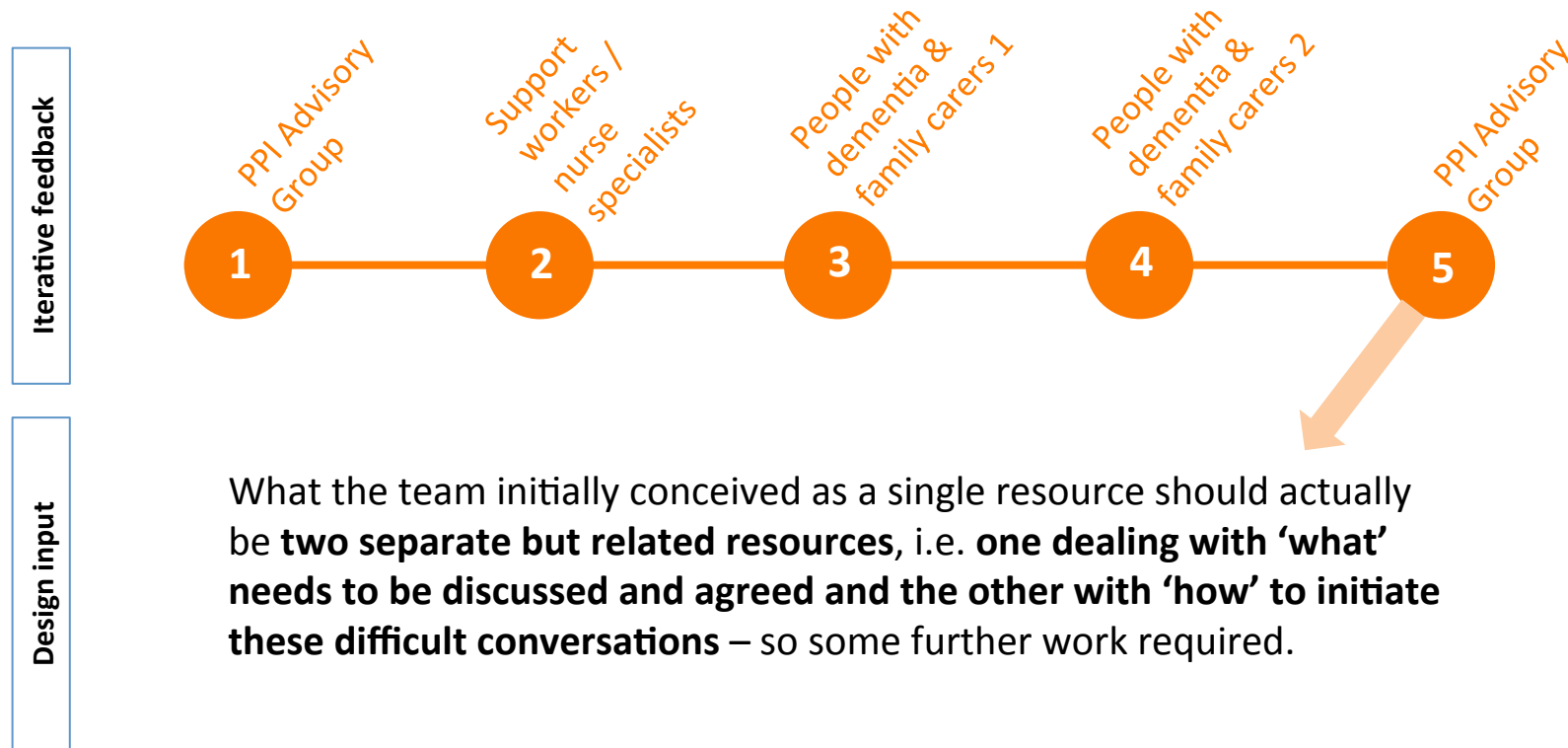
Younger generations (family members and professional carers) preferred the **convenience of the app version enabling direct links** to further web-based resources.

## Findings 3

The CPG was designed to accommodate and reconcile the different stakeholder needs.



## Findings 4





## Limitations

Only people with dementia and carers who were willing to discuss end-of-life care participated in the co-design groups.

The difficulties experienced with recruitment confirmed that many people with dementia and carers prefer not to engage with this topic.

We cannot assume that their views are similar to those of people who participated in the co-design workshops.

## Conclusions

The findings from the SEED programme **corroborate the case for 'rich' stakeholder involvement in translational research processes through a co-design approach.**

Our model of stakeholder involvement has helped the SEED programme **move the discourse from that of designing 'for' to that of designing 'with' its stakeholders in these very sensitive matters around end-of-life – i.e., a more equal and reciprocal relationship.**

Despite our concerns and anxiety around the research topic, **people with dementia and their families were enthusiastic and welcomed and valued research addressing the sensitive and potentially distressing area of end-of-life and in planning ahead for future care.**

## Further details

*In press*

Macdonald, A.S., Neves, S., McLellan, E., Poole, M., Harrison-Dening, K., Tucker, S., Bamford, C. & Robinson. (2107). Co-designing new resources to support better quality end-of-life care with people with dementia and family carers. *Journal of Dementia Care*.



## Acknowledgement

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