


# Living well with multiple conditions in later life - have your say

## GUIDANCE NOTES

### Further information

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## Guidance Notes

This is a companion document to the survey questionnaire 'Living well with multiple conditions in later life – have your say '.

You may be filling out the survey for yourself, or you may be helping somebody else to fill it out.

This document is designed to help you understand the survey and what information we need.

Please read each page of the survey in turn and refer to these notes if you feel you need extra guidance.

This section of the guidance notes refers to **page 2** of the survey, helping you to understand why we are doing the survey and who should complete it.

### Why are we doing this survey?

We know that, as people are living for longer, many people who are aged 80 or older live with many conditions that affect their health.

However, we don't know much about what it is like living with multiple health conditions in later life, and there has been very little research done on how to improve the lives of people who are affected in this way.

We want to ask you what questions you would like researchers to answer about your experiences. We aim to collect this information from a number of older people and health professionals through this survey. We will then turn the information we have collected into a set of priorities for research in this area. We can then better direct the funding of the research to make sure that it looks at what is important to you.

By 'research' we mean investigations that can take place in a variety of settings, not just laboratories or hospitals. These investigations are designed to increase understanding of issues or conditions to help improve older people's lives.

For example, a similar survey was carried out with people who have asthma. Some of them said that they wanted to know if breathing exercises could be effective in helping them cope with their symptoms. As a result, a large research study was funded on this question and the results will mean that doctors will better be able to advise patients with asthma about breathing exercises.

## Who is this survey for?

Our survey on living well with multiple conditions in later life has been designed to be filled out by two groups of people:

- people who are aged 80 or older and have three or more health conditions that affect their daily lives.

OR

- people who live with and / or care for a person who is aged 80 or older and has three or more health conditions that affect their daily lives

## What do we mean by health condition?

We know that the phrase 'health condition' isn't always easily understood and can mean different things for different people. People we have already talked to about this survey have found it difficult to separate what is a 'health condition' from what they think of as all part and parcel of the normal process of getting older.

What we mean by health condition is anything that affects your health to an extent that it affects your ability to live your normal, daily life. For example, you may have hearing loss and struggle to understand what is said in group conversations or on the television, even though you have hearing aids. Or, as another example, you may have arthritis that makes it difficult for you to walk from room to room in your house without help. These are just two examples of many possible ones.

**So,**

**If you are aged 80 or older and have three or more health conditions that affect your daily life in any way then we need to hear from you!**

**If you live with or care for someone who is aged 80 or older and has three or more health conditions that affect their daily lives in any way then we need to hear from you!**

## Section 1 of the survey (pages 3 to 6)

Please only complete this section if you are aged 80 or older and have three or more health conditions. If you are a carer please go straight to section 2.

In this section we want to know about you and how your health conditions affect your life.

**Question 1:** Please let us know how many health conditions you currently have. If you are unsure of the exact number, please give an approximate number.

**Question 2:** Please let us know what your current living arrangements are by ticking the relevant box. If none of the types of arrangement in the list describes your situation, then please explain your living arrangements in your own words under 'Other'.

**Question 3:** We are interested in knowing more about the symptoms that you experience. Please tick the boxes for all the areas that affect you. Remember, we mean everything that affects your daily life, no matter how small. When we have listed 'bladder problems' and 'bowel problems', we mean any problems relating to these issues. For example, do you have struggle to make it to the toilet on time? Or, another example, do you struggle to contain your urine when you cough or sneeze?

**Question 4:** Here we would like a bit of detail about how the symptoms that you have listed in question 3 affect your daily life. For example, if you have mentioned fatigue as a symptom how does this impact upon you? Does it mean that you cannot manage to do the gardening as it is too tiring? Or, do bladder problems mean that you are worried about going somewhere new as you need to know where the toilets are in a new building? You can write as little or as much as you like.

**Question 5:** Here we would like to get an idea of how your medications or other treatments you receive affect your daily life. This can be any pills, syrups, ointments, puffers, injections you take and / or any other aspects of any treatment you have (for example, diet, exercise therapy, talking therapies). For example, if you take painkillers do they make you tired? Can it be hard to remember what tablets you have to take and when? Do you find it hard to travel to make appointments with therapists?

## Section 2 of the survey (pages 7 to 10)

Everyone completing the survey can answer the questions in this section. For each question please write as much or as little as you like.

This is where we want to find out what you think should be the priorities for research. We want to know what is important to you, what questions you have, and what areas you think research should be performed in to help improve the lives of people aged 80 or older with 3 or more health conditions?

**Question 1:** asks about the symptoms you experience. For example, a similar survey in people with Cystic Fibrosis identified that they wanted to know how best to treat the stomach problems that they can suffer from.

**Question 2:** asks about the issues you experience living your day to day life. For example, people with Multiple Sclerosis wanted to know how best they could be supported to manage their condition on their own.

**Question 3:** asks about the medicines that you take. For example, people with Type 1 Diabetes asked about what insulin was the safest and had the fewest side-effects.

**Question 4:** asks about any other treatments you may receive. For example, people who had experienced a stroke wanted to know whether exercise and fitness programmes could be beneficial in improving their quality of life and in helping them avoid another stroke.

**Question 5:** asks about the support or care you may receive. For example, people with dementia wanted to know about the best ways to care for them if they had to be admitted to hospital.

**Question 6:** gives you the opportunity to ask anything else that is important to you that hasn't been covered in any of the other questions.

**THANK YOU FOR TAKING THE TIME TO ANSWER OUR SURVEY.  
WE GREATLY APPRECIATE YOUR HELP.**