

The patient and carer perspective of what's important research for older people with complex health needs

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Older People with Complex Needs, NIHR
Workshop, London, 2nd November 2016

The patient and carer perspective

Quality of life

- Impact on daily living, work, finance, leisure ; mental health and well-being; pain and fatigue; mobility issues; taking a patient-centric versus condition specific approach

Continuity of care

- Service organisation design and delivery – ‘care across organisational and professional boundaries;’ relationships with health care professionals; specialist versus general; communication; data sharing

You don't see the same consultant, I mean I see a different consultant every time I go to the clinic, so you can't get any connection and sort of carrying on the conversation I had last time, you know.

Patient

'You just sort of get yourself a little bit better and then something else seems to crop up. I mean as next week, I'm going to one hospital on Monday, one hospital on Tuesday and another hospital on Wednesday for three different problems. So it's a constant someone saying, "You must do this." And then another doctor saying, "You shouldn't do that. You should do this."

Patient

The patient and carer perspective

Medicines

- Interaction between conditions, medicines and symptoms; understanding and managing medicine regime ‘30 pills a day;’ consequences of long-term medicines use;’ follow-up, monitoring and review

Self-management

- Prioritisation; understanding of enablers and barriers; language, tools, information, new models of care; supporting carers; technology

‘Without my help and encouraging [my father] wouldn’t attend multiple appointments, also dental, chiropodist, optician, GP, flu, vaccine clinics, dietician, physio and others important to his quality of life such as hairdressers and even vet appointments for his little companion dog.’

Carer

Sources

- Public contributors to the workshop
- NIHR Twitter survey of patients and carers, October 2016
- Newcastle James Lind Alliance Priority Setting Partnership on Multi-Morbidity (ongoing)
<http://research.ncl.ac.uk/jlaprioritysetting/>
- healthtalkonline module on 'Living with multiple health problems' for the quotes: <http://www.healthtalk.org/peoples-experiences/long-term-conditions/multimorbidities/overview>

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