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A bite size guide to:

Involving carers

Publications gateway reference: 05428

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Getting started

NHS England is committed to ensuring that the public and patients are at the centre of how we shape our healthcare services. Every level of our commissioning system must listen to, and act on, comments by those who use and care about our services. This feedback should be embedded into our commissioning processes to acknowledge the full value of it.

This bitesize guide offers some principles and practical tips on involving carers in healthcare service planning, delivery and evaluation.

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Why involve carers?

The role of the informal (unpaid) carer is becoming increasingly important in our society. Many patients and service users are supported by relatives, or sometimes friends or neighbours, who provide vital care and help. Caring crosses generations: typical 'kin' carer relationships include people looking after partners; parents looking after children with long-term needs; children and teenagers looking after parents or grandparents; and adults looking after elderly relatives who may have long-term conditions such as dementia, mental health or neurological diseases, or frailty. Many adult carers, particularly older people, also have long-term conditions while young carers have specific needs which require close working with relevant agencies.

Carers are at the front line of providing support and know first-hand what works and, more importantly, what doesn't work as they have a vital relationship with the person that they are caring for. The current law is the Care Act 2014, which recognises the work that carers do, what special responsibilities they have and how their views should be taken into consideration when designing services. Carers UK estimate that 'kin' carers provide £119 billion of care a year.

Getting started

Why involve carers?

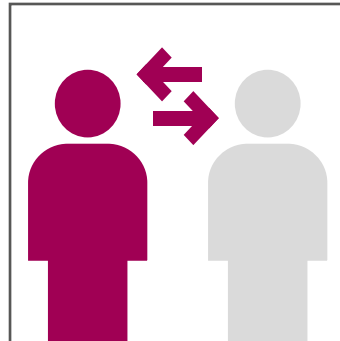
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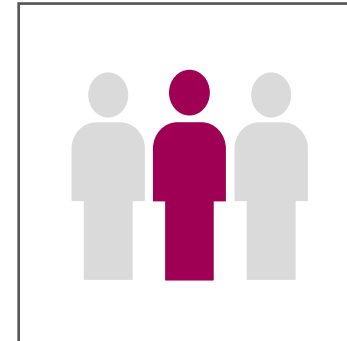
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Core principles



Carers have a close relationship with the people that they care for. Through their caring role, they develop extensive experience of healthcare services and what works or can be improved. A carer's perspective would be of great value to commissioners in the design and delivery of services.



Carers themselves often have support needs, for example, practical support needs such as respite breaks or emotional support to ensure their wellbeing. Commissioners and health services should consider the needs of carers in addition to patients when designing services. This is part of the Care Act 2014.

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Core principles



Building strong relationships with a variety of carer groups / voluntary sector groups and charities at a local level, as well as working with the better-known national carer organisations, would help address some of the inequalities that exist in working with carers who may be under represented or seldom heard.

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Core principles

Case study

Healthwatch Hampshire, Winchester and District Young Carers and Winnall Rock School.

Healthwatch Hampshire held an event to involve Winchester & District Young Carers' Group in identifying services and issues that mattered most to them. In response to the issues raised a series of creative workshops were designed to promote discussion. A series of workshops gave young carers an enjoyable forum in which to explore the services that were most important to them and an opportunity to suggest potential solutions for the issues raised in the initial workshop.

Young carers collaborated with Winnall Rock School to produce a short film illustrating their experiences of services. This film was screened to an audience of carers, young people and health and social care professionals as part of Healthwatch Week in Spring 2014. Filmed contributions around young carers' mixed experiences of the ambulance service led to a further event bringing young carers and South East Coast Ambulance SECAMB staff together. Greater familiarity with ambulance services and young carer-specific guidelines incorporated into staff training were positive outcomes of the event.

Other issues raised by young carers throughout the creative workshops generated innovative ideas for possible solutions including a young carers' ID scheme.

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1. **Include carers as well as patient representatives when recruiting service users to be involved in your work.**
2. **Work with carer organisations / voluntary sector and other local organisations to involve carers who are isolated and are seldom heard.** This will help address issues of equality in the planning and design of services.
3. **National Carer organisations are an excellent source of information on issues impacting carers, and can connect you to various carer networks.**
4. **Work with the local authority, local voluntary sector organisations / charities and faith groups which often provide support to carer groups in your area.** They will often understand the issues that carers face, and can help you link up directly with carers. They will also be able to advise you on barriers to involvement and how to overcome them.
5. **Work with local carers in the design and delivery of engagement activities.** This will help shape the type and variety of activities which can be proposed e.g. a virtual support group.

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- 6. When involving carers in your work, you will need to think about what practical arrangements need to be put in place to support their engagement.** Carers may not be able to make daytime or weekday meetings because of their caring responsibilities, or they may need to arrange a replacement carer while they are attending meetings. Reimbursing out of pocket expenses should be included in the support offered to carers (including covering costs for replacement care)
- 7. Consider the use of digital approaches such as email, text messages and social media e.g. Facebook and Twitter.** Using these methods you can involve people virtually, reducing the need to attend face to face meetings. You can invite them to take part in surveys, online discussions and virtual focus groups.

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Practical Steps

Case study

North Cumbria University Hospitals NHS Trust & Crohn's and Colitis UK.

Patients and carers were supported by the national Crohn's and Colitis UK charity so they could be directly involved in helping to design a new service for Crohn's and colitis sufferers. Crohn's and Colitis UK local groups bring people together who are affected by inflammatory bowel disease, supporting patients, families and carers. They help encourage patient and carer involvement. The co-design drew on carers' expert view of the service formed over many years. Service-users regularly meet staff to tweak the service. Change is on-going.

<http://www.ncuh.nhs.uk/patients-and-visitors/getting-involved.aspx>

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Want to Learn More?

NHS Choices gives carers information on where to find services and support: www.nhs.uk/conditions/social-care-and-support-guide/Pages/what-is-social-care.aspx

Many voluntary sector organisations offer valuable support such as:

The Carers Trust www.carers.org/

Carers UK www.carersuk.org/

The National Council for Voluntary Organisations (NCVO) is the largest umbrella body in England for voluntary and community organisations. It can help to identify local voluntary groups that support carers.

www.ncvo.org.uk/

The Care Act 2014, recognised the need to support carers better: <https://www.gov.uk/government/publications/care-act-2014-statutory-guidance-for-implementation>

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Other Bite-Size Guides

Click on the links below to download each of our '[bite-size guides](#)' to participation. Additional guides are in development.

[Bite-size guide 1 – Principles for Participation in Commissioning](#)

[Bite-size guide 2 – Governance for Participation](#)

[Bite-size guide 3 – Planning for Participation](#)

[Bite-size guide 4 – Budgeting for Participation](#)

Guides 5 -15 are also available via the following link:

<https://www.england.nhs.uk/participation/resources/>

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NHS England's series of 'Bite-size guides' aims to help colleagues plan and deliver the best possible patient and public participation, in line with Transforming Participation in Health and Care.

For further information, please contact england.nhs.participation@nhs.net

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