

# **Response to the Department of Health consultation**

## ***Liberating the NHS: An information revolution***

### **Submission by the Joseph Rowntree Foundation**

**January 2011**

The Joseph Rowntree Foundation (JRF) is pleased to submit the following response to the Department of Health's consultation on *Liberating the NHS: An information revolution*. We would be happy to supply any further information as required.

The Joseph Rowntree Foundation is one of the largest social policy research and development charities in the UK. For over a century we have been engaged with searching out the causes of social problems, investigating solutions and seeking to influence those who can make changes. JRF's purpose is to understand the root causes of social problems, to identify ways of overcoming them, and to show how social needs can be met in practice.

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## **Introduction**

JRF welcomes the government's vision of an information revolution in which people 'have the information they need to stay healthy, to take decisions about and exercise more control of their care, and to make the right choices for themselves and their families'. We particularly welcome proposals to provide unimpeded access for individuals to their own care records, which is vital to putting patients and service users in control. Similarly, bringing about greater integration and consistency between health and social care records systems is long overdue and is an important means to making real person-centred care a reality.

JRF has a long track record in generating good quality research on social care and independent living, particularly as regards groups of people marginalised and disadvantaged, for example through poverty, disability, age or status (such as belonging to a particular social group). Through this research a considerable body of evidence is available which is relevant to this consultation, pointing not only to the inter-connectedness of health and social care but also to the centrality of information to putting people in control of their own lives.

In this consultation document we are pleased to present a selection of our evidence accumulated over the past 10 – 12 years. However, we would be more than willing to bring additional evidence and/or discuss further those included in this document. We are also responding to the consultation 'Liberating the NHS: Greater Choice and Control' which, through its close connection with the subject of this consultation, draws and reflects upon research exploring choice and control, and as one of the prerequisites of achieving this, the importance of good, accessible information.

## **Overview**

On the whole, given our mission and main areas of concern as an organisation, our response is, by definition, less focused on the technical aspects of making the information revolution happen, and more on the resulting information environment as it enables people to have ownership of, and take control over, their own health and care. The overall size of the task is great, and no doubt calls for a comprehensive information strategy, as proposed in the consultation document. Below we highlight a few key considerations and ingredients for this strategy:

- universal access to information on health and social care: especially social care, which is often paid for directly by people themselves as

self-funders. This will be increasingly important in the context of localism and local variation in the available support and services;

- an awareness that specific groups and individuals may often have more intensive information needs both as regards general and specific health and care information, and may also require a targeted and/or individualised approach to providing this information;
- the availability of advice and advocacy to support information;
- co-ordination of information provision across partners and agencies;
- the continued centrality of good face-to-face communication;
- the outcomes that matter the most to patients and service users may not always be those that professionals think important;
- involving patients and service users in designing information systems is an integral part of putting them in control;
- full consideration of what control means for patients and service users in the context of the information revolution.

We believe that such large-scale reform will require careful planning and adequate resourcing, and are concerned about the lack of additional central funding to support this. Considered alongside other large-scale impending reforms across the NHS and the social care system, the forthcoming information strategy (and wider health and social care policy) will have to be particularly alert to the danger of low cost becoming the overriding concern, at the expense of quality of care for all, particularly those already most marginalised.

## **JRF response to consultation questions**

### **Chapter 2: Information for patients, service users, carers and the public**

***Q7. As a patient or service user, in what ways would it be useful for you to be able to communicate with your GP and other health and care professionals on-line, or would you prefer face-to-face contact?***

Unimpeded access to an individual's own health and care records is an important part of the of information exchange between the individual and their health and care professional, as is on-line communication.

However, good face-to-face communication continues to be key, all the more so as it has a central role in the caring relationship as a whole. None of these forms of communication should be mutually exclusive.

Research by JRF exploring prevailing practice in information, advice and advocacy services for older people (Margiotta et al, 2003) sends a consistently strong message confirming the value and centrality of face-to-face communication as a key method through which older people wish to obtain information and advice. Even though this does not reflect unfavourably on other means of gaining information, it serves to underline that face-to-face contact is likely to remain a key part of everyday practice.

Research undertaken among older people and their carers about their needs and experiences of care and support in ten ethnic communities in Bradford further underpins and interprets this finding. Clear and ongoing communication between older persons and their carers about their personal preferences and support needs was seen as particularly important. This was seen as one of the three key aspects of being able to satisfy emotional needs in a caring relationship, in addition to trust and relief from loneliness (Cattan and Giuntoli, 2010).

***Q8. Please indicate any particular issues, including any risks and safeguards, which may need to be taken into account in sharing records in the ways identified in this consultation document.***

Ready access to integrated individual health and care records, and the ease with which a person would be able to pass on large amounts of potentially highly sensitive information about themselves means that much awareness raising and education will be needed for people to understand the implications of exercising this power and make informed decisions. Proper safeguards will also need to be in place to ensure that organisations are not able to put pressure on individuals to reveal more information than they need to. This is of particular concern in the case of people who are vulnerable due to certain health conditions or other personal characteristics.

Being a mental health service user is a case in point: for example JRF research (Lindow and Rooke-Matthews, 1998) showed that being open or not about past mental health treatment was a central dilemma for employees working in mental health services, and for good reason. Those who did reveal such information experienced differential treatment in the workplace, including greater surveillance, treatment emphasising their 'vulnerability', complaints made by them being seen as 'symptoms', accusations of over-identification with patients and other forms of prejudice.

***Q9. What kinds of information and help would ensure that patients and service users are adequately supported when stressed and anxious?***

‘Seriously ill people’ is clearly a key group for whom this question is of critical importance. JRF research (Small and Rhodes, 2001) suggests that understanding and appreciating the issues that frame their experience is a helpful first step in developing the right approach to addressing their information and support needs. Living with uncertainty, hope and the experience of disappointment makes much demand on the time and emotional energy of both seriously ill people and their carers, which has an impact on the space left for other things in their lives. People participating in this research tended to ‘take each day at a time’ and did not look too far ahead. Some of them also chose not to associate themselves publicly with their illness and not to participate in national and local support groups or associations. Part of the coping strategy was for people to develop their own way of managing the flow of information, making decisions about actively seeking information or blocking it off deliberately as they wished. Information needs also varied at different stages of the illness. The information needs of people living with a serious illness and that of their carers may also differ (see also Q12).

The value (and necessity) of repeated opportunities to receive information was brought into focus by research among older people and their carers, as immediately after a health crisis they often underestimated the impact of caring on their lives, and it could also prove difficult to absorb all the information at once (Cattan and Giuntoli, 2010).

Information on how to get advice and advocacy support, and then being able to access this support, is important for all patients and service users to help them make sense of information and make informed decisions. Our work focusing on older people (for example O’Neil and Dunning, 2005; Horton, 2009) found that sometimes they simply needed information but at other times advice and advocacy support was crucial in order to make sense of information and get the service or support they needed. This support could be more important than ever in situations when they feel anxious and stressed.

***Q10. As a patient or service user, what types of information do you consider important to help you make informed choices? Is it easy to find? Where do you look?***

The key message from service users through JRF’s Shaping Our Lives

project (Turner, 2003) regarding information needs was that they wanted to receive information and support that started from and reflected the whole of their lives, and the connections between their health, housing, transport, employment, income and benefits (as well as broader issues around discrimination and equality). Planning and decision-making in later life also involved looking across and assessing information from several areas of life, such as health prospects, family, finances and housing (Hill et al, 2009).

As we have recently indicated elsewhere (Stone, 2010) statutory services that could support those with social care needs would not only include health and mental health, but also housing, transport, education and training, welfare to work, local authority-owned leisure services, children's services (of particular importance to disabled young people and disabled parents), and any others that may be available in particular local authorities. Therefore pieces of information generated by all these services relate to the whole of an individual's life.

The co-ordination of gathering and then providing this information in a way that is person-centred, respectful of the individual's rights and locally relevant is indeed a challenge. However, there are existing good examples that can be built on.

For example, JRF supported the Quality of Life Partnership in Newcastle to develop a more strategic approach to information, advice and advocacy for older people, with the emphasis on ways of working and making existing services more 'older person friendly', as well as effective and efficient. As part of this work, a First Contact scheme was set up involving the use of a simple checklist. This was fed back to a central point, from where information was sent to relevant organisations that made contact with the older person to discuss what services might be available. 'Information NOW' ([www.informationnow.org.uk](http://www.informationnow.org.uk)) is part of this scheme and provides locally relevant web-based information to older people.

One of the strengths of the Partnership's work was the 'Joining the Dots' approach which brought together services and support for older people in the community, including GP practices, intermediate care and community based activity with 'link people' and volunteers (Horton 2009). See also Centre for Policy on Ageing (2011) for further examples from other parts of the UK.

**Q11. What additional information would be helpful for specific groups, e.g. users of maternity and children's health services; disabled people; people using mental health or learning disabilities services; the elderly; others?**

JRF has accumulated a substantial body of research over the past decade regarding the needs and the services available to specific groups of people, such as people with learning disabilities, disabled people, mental health service users, and older people. This body of research suggests that both general lack of information as well as that specific to the needs of a particular group can be a problem, especially when a person has multiple needs. However, it is also clear that supported decision-making is possible where appropriate information is available.

A JRF study examining the involvement of adults with learning disabilities in decision-making in their own healthcare decisions found that many of these adults had not had much useful access to information about their health at all (including, for example, conditions and treatments, as well as basic health information such as the purpose of intimate health checks or sex education). This then became one of the barriers to participation in decision-making (Keywood et al, 1999). However, research with adults with learning disabilities who had *high support needs* also demonstrated that supported decision-making that helped them make choices and take control was possible. This worked through the use of accessible information in simple, appropriate language, and in suitable decision-making environments (Edge, 2001).

Research focusing on supporting disabled parents (Morris, 2003) uncovered a range of *specific issues* that disabled parents wanted information about, including getting access to appropriate maternity services; the implications of particular impairments for pregnancy and parenthood and the impact of pregnancy and parenthood on particular impairments; coping with the negative attitudes of others towards a disabled person becoming a parent; advice on getting assistance with and managing childcare tasks and support with parenting; suitable/available equipment, and what to do if social services initiated childcare proceedings that could lead to losing custody of a child. The research concluded that many of the health and social services professionals who came into contact with disabled parents did not have relevant specialist expertise, therefore it was all the more important to have access to specialist information and advice.

JRF research also uncovered lack of sufficient information provided for

minority ethnic families caring for severely disabled children, for example about the child's disability, and also about the services available for the child and for themselves. Overall, it was found that professionals failed to provide an equal service to speakers of languages other than English (Chamba et al, 1999). Similarly, young disabled people with complex health and care needs making the transition to adulthood did not always receive, or did not receive in a way that made sense to them, the information they needed about medical conditions, treatments and impairments. They also wanted information given directly to them, not to their parents (Morris, 1999).

Drawing out evidence from a body of JRF research on the experiences of black and minority ethnic service users, Chalal (2004) concluded that an end outcome of poor knowledge of services and entitlements (such as the availability of direct payments) was that many gave up on trying to get a service.

***Q12. What specific information needs do carers have, and how do they differ from the information needs of those they are caring for?***

As already indicated, carers of seriously ill people often seemed keener to meet others for support and to find out information than the person they cared for. The same research also concluded that for this reason support organisations' agendas could be dominated by carers' agendas (Small and Rhodes, 2001). However, this finding underlines that carers are a specific audience when it comes to information provision.

### **Chapter 3: Information for improved outcomes**

***Q15. What additional information about outcomes would be helpful for you?***

The key point to recognise is that the outcomes that matter the most to service users may not be the same as those defined by commissioners and providers. This underlines the need for an on-going involvement of service users and user-led organisations in identifying the outcomes that make a difference to people's lives.

Research on user-defined outcomes (Turner, 2003) confirmed that many of the outcomes that users of social care and mental health services wanted to achieve were the 'ordinary things in life' (such as cleaning, shopping, household maintenance), and also about having a comfortable home that was not a 'prison'. Service users thought that providers did not see these ordinary things in life as important and it was very difficult to get support in these areas. Other issues such as



transport and access to buildings were also raised as important outcomes. Crucially, the lack of usable, useful information about available services was seen as getting in the way of being able to identify outcomes in the first place, let alone achieving them.

Evidence from research with disabled young people also shows the importance of user-defined outcomes. The outcomes that mattered the most to these young people as service users were exactly the ones that systems did not measure, such as the provision of information about their condition; being able to go out with their friends and access to communication equipment for those who needed it (Morris, 1999).

The vision of a 'good life' for older people living in care homes for the most part included simple things too, such as 'respect for your routines and commitments', 'being able to choose how you spend your time', 'being treated as an equal and as an adult', 'getting out and about', and perhaps most importantly, 'people knowing and caring about you' (Bowers et al, 2009).

***Q17. For which particular groups of service users or care organisations is the use of information across organisational boundaries particularly important?***

JRF research highlights several groups of people whose experience of health and care services is very poor because they had multiple and/or different types of health conditions and support needs. Invariably, part of the difficulty was to get information across organisational boundaries.

One service user group who would greatly benefit from better integration and standardisation of information is young people with complex health and support needs who are at the point of transition to adulthood. Research undertaken for JRF found that one of the biggest problems planners faced regarding this group was that various health, care, educational and voluntary organisations worked with different definitions of disability and continuing health needs. This made the transition difficult and could result in discontinuity in care. In addition, some registers did not allow for the identification of multiple impairments, therefore young people found themselves falling into one category or another, which got in the way of looking at a person's needs holistically (Morris, 1999).

Another group of people who had a poor service experience due to information not crossing boundaries, even between different types of health services, was those who had physical impairments as well as

mental health support needs (Morris, 2004). Failure to take either type of health condition into account at the expense of the other, and lack of communication between professionals within different services characterised much of the experience of these service users. It was clear from the research that those individual professionals who responded to both needs could make all the difference to a service user's life, yet these same professionals often had to struggle against significant barriers created by structures, procedures and environments.

JRF research discovered a similarly unsatisfactory trend in the provision of pain relief for older people with learning disabilities who develop dementia. This was partly due to lack of recognition of pain by staff (and misinterpretation of signs of pain as challenging behaviour), but information not crossing boundaries also played a part; for example the fact that a person with learning disabilities and dementia may be experiencing pain due to conditions such as arthritis (Kerr et al, 2006).

'Supporting Derek' is a useful resource pack for those working with people with learning disabilities and dementia, recently published by JRF in partnership with the University of Edinburgh (Watchman et al, 2010). The resource pack covers a variety of issues relevant to supporting the growing number of people with learning difficulties who also have dementia, including pain management.

## **Chapter 5: Information for autonomy, accountability and democratic legitimacy**

***Q31. How can a health and social care information revolution benefit everyone, including those who need care most but may not have direct access to or know how to use information technology? This might include those who do not have access to a computer or are remote and cannot access the internet, people using mental health or learning disabilities services, older or disabled people or their carers who may need support in using technology, and those requiring information in other ways or other languages.***

JRF research evidence generally supports the view that diverse groups of the population will have differing levels of ability and/or willingness to use available information, but it also highlights that there will be groups of people for whom the information revolution needs to begin at a different starting point, for example with the provision of accessible information about the way the health and social care systems work and the services available to them. Without this basic knowledge other information, for example about provider performance, or personal care

records, will lack meaning or usefulness for them. Further, it is worth underlining again that advice and advocacy are also key elements in an information revolution that benefits everyone.

Research carried out among Chinese older people and their families (Yu, 2000) illustrates this point: the study found that the majority of older people were not only experiencing language barriers which made it difficult to understand the terms and jargons used in public and social services, but they had insufficient knowledge of the services themselves, as well as of their rights.

The same research also highlighted difficulties in communicating differing cultural perspectives on some health concepts and mental health issues which was not understood and not taken on board by service providers. This suggests that establishing in the first place what is 'relevant information' for different individuals and groups is part of giving people control over their care information.

Recent research among older people and carers in Bradford (Cattan and Giuntoli, 2010) demonstrated that older Chinese people's experiences are still very much alive as far as information needs and provision are concerned. For both older people and carers in Bradford lack of information about services was a major source of frustration, and it also meant that they were often missing out on important services. As already mentioned, older people needed information about available services at different points in time. A major concern was the lack of effective communication between different service providers and between services and older people and carers. Therefore, having more integrated information systems across health and social care could contribute to reducing fragmentation of services, and to a greater ability to meet the needs of older people, if coupled with good personal communication.

JRF endorses the view that dedicated action will be needed on the part of health and adult social care services to ensure that the benefits of greater access to better information are enjoyed equally across different groups in society. However, it remains a concern that among those who may have high care needs a higher proportion do not have access to information technology. The government's recent Manifesto for a Networked Nation (Race Online 2012, 2010) confirms that 48 per cent of disabled people and more than three-quarters of older people over 75 are offline. Moreover, the manifesto suggests that around four of the ten million people not using the internet are from the most socially

disadvantaged groups. While initiatives aimed at reducing digital exclusion such as Race Online 2012 are promising, it is likely that more targeted support is needed for some groups in order to ensure that already existing health inequalities are not exacerbated by digital exclusion in the course of implementing an information revolution in the NHS.

A JRF investigation of whether the internet opens up opportunities for disabled people found that although they seemed interested, disabled people faced a number of barriers when accessing the internet, even those who had already become internet users. Barriers included the high cost of getting online (including computer costs), problems with getting access to the right assistive devices, and some websites being difficult to navigate with assistive devices (Pilling et al, 2004).

A review of the evidence for JRF also raised questions about the attractiveness and efficacy of making computers available at public spaces as a means of extending the benefits of the digital age to socially excluded groups. This was, for example, because locations such as libraries, colleges and schools were not considered by many as 'part of their lives', while the research evidence also pointed to difficulties with people conducting business involving personal information in public spaces (Loader and Keeble. 2004).

## **Chapter 6: Setting the direction – the information strategy**

### ***Q34. Are there any critical issues for the future of information in the health and adult social care sectors that this consultation has not identified?***

The consultation document quotes the principle of 'no decision about me without me'. In our view this should be extended to developing the information environment itself, as it will shape both systemic and individual decisions about health and social care for some time to come. This contribution seems particularly relevant in enabling people to interpret their records, and needs to involve a range of service users.

We have emphasised throughout our response that information in itself is not always enough: access to good advice and advocacy are also key elements in an information revolution, so that those patients and service users who need it can get help with making sense of information and can access the services and support they need (for example O'Neil and Dunning, 2005; Horton, 2009).

As JRF research shows, user involvement in shaping health and care services has at best a patchy recent history beset by tokenism, power differentials and closed professional cultures. This applies in a variety of contexts including service users working with both service providers and commissioners. However, recent research also identified more progress in involving users in commissioning social care than health care services (Branfield and Beresford, 2006; Mauger and Deuchars, 2010). Despite the track record, it is both sensible and worthwhile to get this right, as our evidence shows that, for example, strategies developed with older people (as service users) were more likely to succeed (O'Neil and Dunning, 2005).

Two critical questions we propose to add therefore are:

**What measures will need to be in place to ensure that the new information environment enables patients and service users to get access to good quality advice and advocacy to make the best use of information?**

**How will patients and service users be involved in developing the information environment that truly enables them to be in control of decisions about their health and care?**

## **Conclusion**

JRF welcomes and broadly supports the government's intention to create an information infrastructure which results in good quality, relevant and purposeful information across the health and care systems, ultimately enabling individuals to take control of their health and care. However, we remain concerned about the proposed funding arrangements for this large-scale reform and the lack of focus on critical elements to support information, especially for those who are already marginalised and may face additional barriers. In particular, our evidence highlights the importance of access to advice and advocacy alongside the provision of information. We strongly believe that if this is to be a true information revolution, it must aim to take with it marginalised groups who in the past had limited or no opportunity to participate in, and have control over, decisions about their health and care.

In our view, setting out clearly what 'control' for patients and service user means, and linking this directly to greater choice and control for patients and service users, is also at the heart of achieving an information revolution. Although as part of the vision this is already present in the

consultation, we believe that at present the main emphasis is on two broad aspects: individuals' access to their records and their freedom to share their information. In our view the concept of control needs to be considered at two levels: at a more immediate level, it should address the individual's ability to influence the content of their records and the ways the data in the records is used. At the next, and arguably more important, level the concept should set out how the information enables individuals to be in control over the way their health and social care is delivered.

In our responses to consultation questions we have provided evidence to underline the point that making the information revolution work for a wide range of people is indeed a large and comprehensive task which needs to take full account of the differing points people are at in their levels of knowledge and information needs. We have also cited evidence to show that in some cases it is more important that the individual is able to control the flow of information than to actually access it. Both of these points should form part of the concept of control over information.

Ultimately, the purpose of health and care information is to empower shared decision-making, and this is where real control lies. Perceived this way, access to records is a first step, but depending on the individual, additional pieces of information need to slot in place in order to enable true 'control'. We have argued that this information may include addressing gaps in general health education, how the health and social care systems work and what services are available, as well as meaningful information on particular health conditions. Equally, providing tailored help for people with interpreting records and getting the services and support they need through good advice and advocacy is an important intermediate step. Without all this an individual's 'control' over decisions regarding their health and care is seriously curtailed or non-existent.

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## References

All JRF publications are available at [www.jrf.org.uk/publications](http://www.jrf.org.uk/publications) unless otherwise stated.

Bowers H, Clark A, Crosby G, Easterbrook L, Macadam A, MacDonald R, Macfarlane A, Maclean M, Patel M, Runnicles D, Oshinaike T and Smith C (2009) Older people's vision for long term care. York: Joseph Rowntree Foundation.

Branfield F and Beresford P (2006). *Findings*: 'Making user involvement work: supporting service user networking and knowledge', JRF *Findings* (Ref 1966). York: Joseph Rowntree Foundation.

Cattan M and Giuntoli G (2010) Care and support for older people and carers in Bradford. York: Joseph Rowntree Foundation.

Centre for Policy on Ageing (2011) *Solutions*: 'How can local authorities with less money support better outcomes for older people?' JRF *Solutions* (Ref 2542). York: Joseph Rowntree Foundation.

Chahal K and Ullah A (2004) Experiencing ethnicity: Discrimination and service provision. York: Joseph Rowntree Foundation. Available at: [www.jrf.org.uk/sites/files/jrf/914.pdf](http://www.jrf.org.uk/sites/files/jrf/914.pdf) (Accessed on 11 January 2011).

Chamba R, Ahmad W, Hirst M, Lawton D and Beresford B (1999) Minority ethnic families caring for a severely disabled child. York: Joseph Rowntree Foundation.

Edge J (2001) *Findings*: 'Demonstrating control of decision by adults with learning difficulties who have high support needs', JRF *Findings* (Ref 021). York: Joseph Rowntree Foundation.

Hill K, Sutton L and Cox L (2009) Managing resources in later life: Older people's experience of change and continuity. York: Joseph Rowntree Foundation.

Horton C (2009) *Solutions*: 'Creating a stronger information, advice and advocacy system for older people', JRF *Solutions* (Ref 2409). York: Joseph Rowntree Foundation.

Kerr D, Cunningham C and Wilkinson H (2006) Pain management for older people with learning difficulties and dementia. York: Joseph Rowntree Foundation.

Keywood K, Fovargue S and Flynn M (1999) *Findings*: 'Adults with learning difficulties' involvement in health care decision-making', JRF *Findings* (Ref 029). York: Joseph Rowntree Foundation.

Lindow V and Rooke-Matthews S (1998) *Findings: 'The experiences of mental health service users as mental health professionals'*, JRF *Findings* (Ref 488). York: Joseph Rowntree Foundation.

Loader BD and Keeble L (2004) *Challenging the digital divide? A literature review of community informatics initiatives*. York: Joseph Rowntree Foundation.

Margiotta P, Raynes N, Pagidas D, Lawson J and Temple B (2003) *Are you listening? Current practice in information, advice and advocacy services for older people*. York: Joseph Rowntree Foundation.

Mauger S, Deuchars G, Sexton S and Schehrer S (2010) *Involving users in commissioning local services*. York: Joseph Rowntree Foundation.

Morris J (1999) *Transition to adulthood for young disabled people with complex health and support needs*. York: Joseph Rowntree Foundation.

Morris J (2003) *The right support: Report of the Task Force on Supporting Disabled Adults in their Parenting Role*. York: Joseph Rowntree Foundation.

Morris J (2004) *Findings: 'Services for people with physical impairments and mental health support needs'*, JRF *Findings* (Ref 574). York: Joseph Rowntree Foundation.

O'Neil A and Dunning A (2005) *Briefing: Is information power? Older people, information, advice and advocacy* (Ref 0615). York: Joseph Rowntree Foundation.

Pilling D, Barrett P and Floyd M (2004) *Findings: 'Does the Internet open up opportunities for disabled people?'* JRF *Findings* (Ref 524). York: Joseph Rowntree Foundation.

Race Online 2012 (2010) *Manifesto for a networked nation*. Available at: [http://raceonline2012.org/sites/default/files/resources/manifesto\\_for\\_a\\_networked\\_nation\\_-\\_race\\_online\\_2012.pdf](http://raceonline2012.org/sites/default/files/resources/manifesto_for_a_networked_nation_-_race_online_2012.pdf) (Accessed on 11 January 2011).

Small N and Rhodes P (2001) *Findings: 'User involvement and the seriously ill'*, JRF *Findings* (Ref 271). York: Joseph Rowntree Foundation.

Stone E (2010) *Response to the Law Commission Consultation on Adult Social Care*. York: Joseph Rowntree Foundation. Available at: [www.jrf.org.uk/sites/files/jrf/consultation-law-commission-adult-care.pdf](http://www.jrf.org.uk/sites/files/jrf/consultation-law-commission-adult-care.pdf) (Accessed on 11 January 2011).



Turner M (2003) *Shaping our lives – from outset to outcome. What people think of the social care services they use*. York: Joseph Rowntree Foundation.

Watchman K, Kerr D and Wilkinson H (2010) *Supporting Derek: A practice development guide to support staff working with people who have a learning difficulty and dementia*. York: Joseph Rowntree Foundation.

Yu W K (2000) *Chinese older people: A need for social inclusion in two communities*. Bristol: Policy Press for the Joseph Rowntree Foundation.