Working with healthcare professionals to increase carer awareness, identification and referral

20th April 2012

1.0 Background

With funding from the Department of Health, Carers Trust are working with the Queens’ Nursing Institute (QNI), and the Royal College of Nursing (RCN), to develop the capacity of nurses to identify, refer and support unpaid carers.

1.2 Methodology

Following liaison with both the QNI and RCN, it was agreed that their members would be asked to complete an online survey. This was launched to members of the QNI on (date) and finished on (date). The same survey is about to be distributed to members of the RCN. The findings below are taken from the surveys completed by QNI members; once the RCN members have completed the survey as well, their responses will be added to the information already generated.

The information that is ultimately produced through this process will be used to enable Carers Trust to produce the most relevant, accurate and practical information to nurses and other healthcare professionals to increase the early identification of carers.

The survey was emailed by the QNI to 1900 of its members and 338 responses were received; of these, 306 completed the entire survey, with 32 respondents only answering some questions (however, these 32 respondents still answered the majority of the questions asked).
1.3 Respondent demographics and baseline data

The largest group of respondents to the survey were District Nurses (Fig.1.2.1.) although there were responses from nurses across a wide range of other specialist areas. The respondents were asked how many carers they believe that they come into contact with each week through undertaking their normal working responsibilities. Fig.1.3.1. shows their answers to this question.

When asked how confident they felt in their ability to identify when someone has a caring role 95% of respondents said that they felt either ‘Very confident’ (49.3%), or ‘Confident’ (45.7%). Only 4.5% of respondents felt ‘Not very confident’ (3.9%), or ‘Not at all confident’ (0.6%) in this. Furthermore, 89.7% of respondents felt ‘Very confident’ or ‘Confident’ that they could engage with these carers and identify that they need support (see Fig.1.3.2.).

Fig.1.3.1. Chart demonstrating the number of carers respondents believe they meet each week

Fig.1.3.2. Chart demonstrating the respondents’ confidence in engaging with carers and identifying that they need support
However, 39.8% of respondents do not feel confident signposting carers to support offered by the local voluntary sector; 33.4% were ‘Not very confident’, and 6.4% ‘Not at all confident’ (Fig.1.3.). Whilst it is positive that 57.6% of respondents were confident about signposting to these local services, this survey suggests that there is an opportunity to increase knowledge of local voluntary support services amongst healthcare professionals. There also may be other issues such as a lack of confidence in the ability of voluntary sector organisations to support carers (which suggests the need for further investigations in certain areas);

“I find it challenging as I have very little to offer in way of support to carers. I can listen and suggest they contact the local carer’s line, but I do not have access to other help for them” (Community Oncologist)

Respondents were asked to list all of the issues that they feel are important to carers, and selected the following as being particularly important (70% of respondents or above selected this as an issue):

- Carers having time to themselves (94.3%)
- Stress (90.4%)
- Financial concerns (82.4%)
- Carers not knowing where to go for help (86.6%)
- Depression and/or anxiety (80.3%)
- Carers’ physical health and wellbeing (77.9%)
- Loneliness (75.5%)
- Relationship problems (72.5%)

The following issues were also seen as important by respondents:

- Carers feeling that they are not being heard (69.3%)
- Nutrition (37%)
- Problems at work/school (51.9)
- Carers not understanding the treatment and medication for the cared-for person (63.9%)
- Carers not being seen as a partner in the provision of the cared-for persons’ healthcare (66%)
Whilst the results from this survey indicate a strong awareness of many of the issues that carers face as part of their daily lives, there are some issues that occur daily for carers which a significant number of healthcare professionals do not see as areas for concern.

“Carers are the unsung heroes in my opinion. I see a lot of very, very good carers exhausted, frustrated and not getting any respite. Social Services are struggling with the work load [...] Patients, GPs, family members and hospital staff call the Districts Nurses to help sort out problems and approx. 80% of the problem is a Social problem. I myself get frustrated that I cannot help these people because of not knowing what is available to them” (District Nurse)

Notably, this includes information around the care the cared-for person is receiving, and the carer’s role within the provision of this. Previous research undertaken by the Princess Royal Trust for Carers shows that this can be a significant concern for carers; particularly new carers who are unused to their role and new situations.

“Often the needs and choices of the carers can conflict with those of the client which can cause friction and at times uncertainty about how to resolve these differences and conflicting needs” (Mental Health Nurse)

The Triangle of Care - a successful piece of work currently being undertaken by Carers Trust - demonstrates the value of involving carers fully in the care provision system, and making sure that they are aware of how best to support the cared-for in collaboration with the healthcare professional. This can lead to improved health and well-being for both the carer and the cared-for, and reduce pressure on healthcare services.

As such, the results from this survey combined with experience developed through other work-streams suggests that developing information to increase the understanding of healthcare professionals around the issues which received a low score above would have both short- and long-term benefits for carers, patients, and healthcare professionals.

Fig.1.3.4. Chart showing how respondents are able to interact with carers when working
When asked about how they engage and work with carers (Fig.1.3.4.), the respondents indicated that in the main they have the time to identify and engage with carers (61.3% ‘Agreeing’ or ‘Strongly agreeing’ with this). However, when asked if they have information about local support services for carers 40% of respondents either ‘Disagreed’ or ‘Strongly disagreed’ that they have this information. It should be noted that 37% of respondents did ‘Agree’ or ‘Strongly agree’ that they have access to information about supporting carers in the local environment.

This suggests that whilst there are opportunities for healthcare professionals to engage with carers, a lack of information available to professionals may be stopping them from utilising this time fully – or other reasons, all of which would merit further investigation. Furthermore, whilst 51.3% of professionals feel that they have time to engage with carers, 18.2% ‘Disagree’ or ‘Strongly disagree’ that this is the case (with 19% of respondents undecided); this demonstrates a clear opportunity for improvement.

When asked whether they have access to lots of useful information about carers in general, 39.8% of respondents agreed and 37.6% disagreed. Again, this demonstrates an opportunity for more information about carers to be made available to healthcare professionals.

Based on the findings from this survey, it is fair to suggest that more information about carers in general, and support available for them at a local level, would help healthcare professionals to use the time that they have available when encountering carers to engage more fully with them. This then has the potential to increase the support that carers receive, increasing health and wellbeing for carers and cared-for persons, and improving healthcare services by reducing demand and improving joint working.

The 90.9% of healthcare professionals who are aware of carers issues (Fig.1.3.4.), further reinforces this finding, as there is a clear awareness of the need to support carers (this is particularly true when this is considered in conjunction with the responses to the issues that healthcare professionals believe are affecting carers – see above).

“[The problem is] not having the time or resources to offer them the support or signpost them to appropriate services. The culture of district nursing becoming increasingly dominated by task - time for holistic family centred care is sadly becoming less of a priority as clinical pressures take precedence” (District Nurse)

Finally, it is worth noting here that only 17.6% of healthcare professionals found working with carers challenging. Based on the findings from this survey discussed above it could be concluded that, as healthcare professionals are confident that they have the time to talk to carers and are able to engage with them in a positive way, that is not challenging, then there should be an increase in the resources available to support them. This could lead to a significant increase in carer referral, support, and cross-organisational identification.
1.4 Examining potential support

The need for an increase in resources is reinforced when examining the respondents’ answers to questions regarding what information they would find useful about carers (Fig.1.4.1.), and how carers can be better supported by healthcare professionals (Fig.1.4.2., and Fig.1.4.3.).

Examining the answers to what information healthcare professionals feel would be useful for them to have about carers, it is clear that information relating to: the challenges facing carers; general information about carers; and government policy in relation to carers, would all be relevant (Fig.1.4.1.).

Fig.1.4.1. Chart showing how useful respondents feel different information about carers would be

Fig.1.4.2. Chart demonstrating how useful respondents felt that information about engaging carers would be to support them in their day-to-day work
As can be seen from the chart, at least 70% of respondents felt that this information would be ‘Useful’ or ‘Very useful’.

Considering how different types of information would help healthcare professionals to engage with carers and discuss their caring role with them (Fig.1.4.2.), respondents again indicated that they felt that this would be useful.

When asked if information on approaching carers who do not identify themselves as a carer, and how other professionals have engaged with carers would be useful, at least 70% of respondents indicated that this would be ‘Useful’ or ‘Very useful’. When asked if a clearer definition of the word carer would be beneficial to engaging with carers, the largest proportion of respondents felt that this would only be ‘Somewhat useful’ (31.3%), and 48.2% felt that it would be ‘Very useful’ or ‘Useful’. Overall this indicates that information to help professionals engage with carers would be very beneficial.

Finally, when considering what information would support healthcare professionals when engaging with carers, respondents were asked to consider how useful different information would be to help them signpost carers to support services. Again, this was seen as very important by the respondents, with every type of information being seen as ‘Very useful’ by the largest proportion of respondents (Fig.1.4.3.).
Fig.1.4.3. Chart showing how useful healthcare professionals feel that information about support services available to carers would be

Based on these findings, it is clear that respondents feel that having information about support services available to carers would be extremely beneficial. This supports the earlier findings that many respondents feel that they have the time to engage with carers, and the ability to do so, but lack the information necessary to make the most effective use of these opportunities for engagement (see section 1.2).

1.5 Examining how best to distribute information and resources

After being asked to consider what information would best support their work with carers, healthcare professionals were asked how best this information could be made available to them. This was considered in two stages: the physical form that the information could take to be used on a day-to-day basis; and how best this information could be distributed to professionals.

Considering the way in which information could be provided for everyday use by healthcare professionals, respondents mainly focussed on information that would support individual study, such as E-bulletins, online resources and factsheets (see Fig.1.5.1.). With the exception of posters, all other mediums suggested were seen as mainly ‘Very useful’ or ‘Useful’ as a means of providing information.

“[I need to know] How to find the help they need when they need it, and not several days later; what is Social Services role and how to contact them and get help from them” (District Nursing)

“I think a national list of current services available to carers would be helpful as sometimes the carers I work with live outside of my area and I am not always aware of services in other areas” (School Nurse)
Fig. 1.5.2. demonstrates how useful respondents felt some specific tools and resources would be in supporting carers. The guidance on how to talk to carers (50.8%), and awareness raising materials (55.1%) were seen as ‘Very useful’ or ‘Useful’ by the respondents, and could easily be developed into appropriate mediums such as factsheets and leaflets, which the previous findings indicate would be most useful as practical tools. Also, simple referral forms to allow nurses to pass carers’ details on to GP surgeries and carers’ organisations, ensuring cross-organisational identification and support for carers, were seen as something that would be very effective (81.2% of respondents indicating that these would be ‘Very useful’ or ‘Useful’).

![Chart showing how useful different mediums are for supporting the daily work of healthcare professionals who engage with carers](image)

**Fig.1.5.1.** Chart showing how useful different mediums are for supporting the daily work of healthcare professionals who engage with carers

Finally, respondents were asked to consider the best way in which this information and these resources could be distributed to them (Fig.1.5.3.). A range of potential options were considered, and with the exception of social media, all mediums received a strong recommendation from respondents.
Fig. 1.5.2. Chart showing how useful specific resources would be in supporting healthcare professionals who engage with carers.

Fig. 1.5.3. Chart showing how useful various mediums are for delivering information and resources to healthcare professionals.
The two key areas which stand out from this are the delivery of information through existing resources and channels, such as professional journals and websites, and also via individual learning mediums, such as e-learning modules and online videos: information that professionals can access at times that suit their work environment and schedule (Fig.1.5.3.). There was some enthusiasm for face-to-face training (63.7% seeing this as ‘Very useful’ or ‘Useful’), although the practicality of delivering this training may be prohibitive to its overall value when compared with other mediums; the significantly lower support for conferences could be indicative of the difficulty of mass face-to-face training, particularly when considering individual workloads and demands.

Fig.1.5.4. Chart showing respondents’ opinions of example referral form (see Appendix One)

The final part of the questionnaire asked respondents to comment on a proposed referral form (see Appendix One), which could be used to pass on carer details to GPs and local support services by arrangement. The purpose of this was to ascertain what style of form would be most practical for health professionals, and is based on a form that has been successfully trialled in Salford, Northern England.

The responses were very positive (Fig.1.5.4.), suggesting that it contains all of the necessary information and would be simple and effective to use, without infringing on the professionals’ available time: 88% of respondents ‘Strongly agree’ or ‘Agree’ that they would have time to complete this form; and 79.1% ‘Strongly agree’ or ‘Agree’ that they would use this form in their work. This indicates again, and reinforces earlier findings, that useful information and resources would help to develop the opportunities for, and effectiveness of, healthcare professionals’ engagement with carers.
2.0 Conclusions

Overall, this questionnaire has shown that healthcare professionals feel that they are aware of some carers’ issues, and feel – in the main – able to identify carers. However, there is a clear desire amongst respondents to receive more information about carers, and this survey has identified some specific and general gaps which can be filled by this information.

The information collected from this questionnaire has also investigated the best format for information to be distributed in, and the most effective way to do so; concise, practical information sheets and leaflets, which can be accessed at any time through existing professional mediums such as websites and journals.

In the light of this survey, there is a clear need to develop these resources and make them available to as many healthcare practitioners as possible, providing relevant and up-to-date information that will support professionals in their engagement with carers, and help them to direct carers to the local support services that exist.

Finally, whilst this piece of research has begun to answer many questions, it has also highlighted a wide range of areas which will require further investigation, i.e., such as why respondents felt that some issues were important to carers? To further develop the information gained through this initial survey, it would be beneficial to continue to expand this research. Developing qualitative research methodologies, such as focus groups, interviews, and more semi-structured surveys focussing on specific issues, will help to progress this research and develop tailored, relevant and up-to-date information that addresses unmet need amongst healthcare professionals.
Appendix One; Example referral form for healthcare professionals to use to pass on carer details to GPs and voluntary support services

Carer registration and referral form

I look after someone who can’t get by on their own
Please make a note that I am a carer on my medical records
Please refer me to my local Carers Centre for a Carers Information Pack
(tick as appropriate)

Your details:
Full name: ..................................................
Date of birth: ..............................................
Your GP Practice: ........................................... 

Alternatively, you can contact your local Carers Centre directly:

N.B. This section will be formatted to allow information about local centres to be added quickly and easily, and then saved for future use.

Please hand this completed form to a member of staff at your GP Practice
Subject: “HELP BRING CARERS OUT OF THE SHADOWS”

HELP BRING CARERS OUT OF THE SHADOWS

There are around six million unpaid carers in the UK, and every year two million people move in and out of caring roles. A large number of these people are not identified as carers, and as a result are missing out on much-needed support, with serious consequences, both for their own health and, in some cases, for the health of the person they care for.

Because the QNI represents nurses whose work in the community provides them with opportunities to encourage carers to access support, the Princess Royal Trust for Carers and Crossroads Care have invited us to work in partnership with them to develop information and resources to help your identify and refer carers as easily and effectively as possible.

Here’s how you can help

All you have to do is click on the link below and you’ll be taken to an online questionnaire, which should only take a few minutes to complete. Your answers to the questions will help the Trust and Crossroads to develop resources that are specifically tailored to your role as a community nurse.

Many thanks.

http://www.surveymonkey.com/s/Working_with_carers-what_support_do_you_need

“From my perspective I find it empowering to offer support to a carer who is clearly at her wits end. It is a life line for someone who sees caring for a loved one as a natural duty and their life stops to be as important”

Julie Trenbath – Practice Nurse, Salford
Appendix Three; Word version of the survey – note that this was distributed ‘live’ through Survey Monkey

Working with carers: what support do you need?

The following questions refer to the support you provide to unpaid carers in your role as a healthcare professional (where a carer is defined as someone who looks after a partner, relative, friend or neighbour who would not be able to get by on their own due to old age, frailty, illness, disability, mental ill health or addiction). Your answers will help us design resources to help you identify, support and refer carers more easily in future – in particular, the ‘hidden’ carers who are not currently accessing support.

Please note that throughout the survey there are multiple choice questions, asking you to rate a range of topics on a scale. The various questions within these topics can be rated independently of each other, i.e. they could all be rated ‘useful’

About you

1. Please indicate your primary area of work (NB: on Survey Monkey this will be a tick-box list);

<table>
<thead>
<tr>
<th>Adult Care</th>
<th>Alcohol &amp; Substance Misuse</th>
<th>Cardiovascular</th>
<th>Children &amp; Young People’s</th>
<th>Discharge Planning &amp; Continuing Healthcare</th>
<th>District Nursing</th>
<th>End of Life Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare Assistant</td>
<td>Health Visiting</td>
<td>Learning Disabilities</td>
<td>Mental Health</td>
<td>Midwifery &amp; Fertility</td>
<td>Occupational Health</td>
<td>Older People’s Care</td>
</tr>
<tr>
<td>Pain &amp; Palliative Care</td>
<td>Practice Nursing</td>
<td>Public Health</td>
<td>Specialist Nurse</td>
<td>Other*</td>
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</tbody>
</table>

If ‘other’ then please specify:

2. In a typical week, how many carers do you come into contact with?

   a. 0
   b. 1 - 5
   c. 6 - 10
   d. More than 10
3. Do you feel confident in your ability to identify when someone has a caring role?
   a. Very confident
   b. Confident
   c. Not very confident
   d. Not at all confident
   e. Unsure / No opinion

4. If you identify someone who has a caring role, how confident do you feel in engaging with them and identifying that they need support?
   a. Very confident
   b. Confident
   c. Not very confident
   d. Not at all confident
   e. Unsure / No opinion

5. When engaging with carers, how confident do you feel that you can signpost them to local services provided by the voluntary sector?
   a. Very confident
   b. Confident
   c. Not very confident
   d. Not at all confident
   e. Unsure / No opinion

6. Please indicate which of the following you think are issues for carers (please indicate as many issues as you feel are relevant):
   a. Time to themselves
   b. Money worries
   c. Not knowing where they can go for help
   d. Not being heard
   e. Depression and/or anxiety
   f. Their physical health and wellbeing
   g. Nutrition
   h. Relationship problems
   i. Problems at work/school
   j. Loneliness
   k. Stress
   l. Not understanding treatment and medication for service user
   m. Not being seen as a partner in the service user’s healthcare
7. Please indicate the extent to which you agree or disagree with the following statements:

<table>
<thead>
<tr>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Not applicable/don’t know</th>
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</thead>
<tbody>
<tr>
<td>When working, I have time to identify and engage with carers</td>
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<tr>
<td>I have lots of information about how carers can be supported locally</td>
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<tr>
<td>I have access to lots of useful information about carers</td>
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<td>I am aware of carers issues</td>
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<td>I find working with carers challenging*</td>
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*If you find working with carers challenging in some way, please explain why this is below

Information that could be helpful to you in supporting carers

8. Please indicate how useful the following information about carers would be to you:

<table>
<thead>
<tr>
<th>Very Useful</th>
<th>Useful</th>
<th>Somewhat useful</th>
<th>Not very useful</th>
<th>Not at all useful</th>
<th>Unsure</th>
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<tbody>
<tr>
<td>What the challenges facing carers are</td>
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<td>General information about carers</td>
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<td>Government policy in relation to carers</td>
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</table>
9. Please indicate how useful the following information would be in helping you to engage with carers, and to discuss their caring role with them:

<table>
<thead>
<tr>
<th></th>
<th>Very Useful</th>
<th>Useful</th>
<th>Somewhat useful</th>
<th>Not very useful</th>
<th>Not at all useful</th>
<th>Unsure</th>
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</thead>
<tbody>
<tr>
<td>A clear definition of the word carer</td>
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<td>How to approach a carer who doesn’t see themselves as a carer</td>
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<tr>
<td>How other healthcare professionals have successfully engaged with carers</td>
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10. Please indicate how useful the following information would be in helping you to support carers:

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<th></th>
<th>Very Useful</th>
<th>Useful</th>
<th>Somewhat useful</th>
<th>Not very useful</th>
<th>Not at all useful</th>
<th>Unsure</th>
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<tr>
<td>What national support services are available (including voluntary services)</td>
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<td>What local support services are available (including voluntary services)</td>
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<td>How to develop links with these services (including voluntary services)</td>
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<td>How to develop links with other services that can support carers, e.g. GPs and pharmacists</td>
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11. Please use the space below to tell us about any other information that you feel would be beneficial in supporting you in your work with carers.
What resources/tools would best support you as a healthcare professional when working with carers?

12. Considering your answers about what information would be most useful to you, please indicate how useful the following formats would be for use in your day-to-day role:

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<thead>
<tr>
<th></th>
<th>Very Useful</th>
<th>Useful</th>
<th>Somewhat useful</th>
<th>Not very useful</th>
<th>Not at all useful</th>
<th>Unsure</th>
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<tr>
<td>Concise factsheets</td>
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<td>Posters</td>
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<td>Leaflets</td>
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<td>E-bulletins</td>
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<td>Online resources</td>
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13. Please indicate how useful the following specific tools and resources would be in supporting your work with carers:

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<th></th>
<th>Very Useful</th>
<th>Useful</th>
<th>Somewhat useful</th>
<th>Not at all useful</th>
<th>Not at all useful</th>
<th>Unsure</th>
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<tr>
<td>Guidance on ‘how to talk to carers’</td>
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<td>Awareness-raising materials, e.g. posters</td>
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<td>Simple referral forms to be passed to GPs and local carers centres</td>
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14. Please use the space below to tell us about any other tools/resources that you feel would be beneficial in supporting you in your day to day work with carers. What form would these resources take, e.g. information sheets, training, etc.?
15. Please indicate how useful the following would be as a means of providing you with information relating to carers:

<table>
<thead>
<tr>
<th>Method</th>
<th>Very Useful</th>
<th>Useful</th>
<th>Somewhat useful</th>
<th>Not very useful</th>
<th>Not at all useful</th>
<th>Unsure</th>
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<tr>
<td>Emails</td>
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<td>Professional journals, newsletters, bulletins etc.</td>
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<td>Professional websites</td>
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<td>Social media, e.g. Twitter</td>
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<tr>
<td>Conferences</td>
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<td>Workshops</td>
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<td>Face-to-face training</td>
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<tr>
<td>E-Learning modules</td>
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<tr>
<td>Online videos, presentations etc.</td>
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</tbody>
</table>

Making the resources as useful and relevant as possible

*Attached to this survey is a sample referral form, and instructions on how to use it. Please refer to this when answering the following questions.*

16. With reference to the referral form, please indicate the extent to which you agree or disagree with the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Unsure / No opinion</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The form is too complicated</td>
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<tr>
<td>I would have time to complete this form</td>
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<td>I would use this form in my work</td>
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<tr>
<td>The form contains all necessary information</td>
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<td>The information sheet is useful</td>
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<tr>
<td>The information sheet contains all the necessary information</td>
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</tbody>
</table>

17. Please use the space below to provide any other feedback on this sample referral form.
Thank you for taking the time to complete this survey. Your answers will help us make sure that we are able to develop relevant information and resources to assist you in supporting unpaid carers.