People's feedback about the Wessex Rapid Investigation Service

For the Clinical Reference Group

11 March 2020

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Introduction

This report is based on qualitative feedback from 40 patients and 1 carer. They were some of the first people to use and be discharged from the Wessex Rapid Investigation Service (RIS) for suspected cancer, although none were found to have a malignancy. The interviews took place between the beginning of October 2020 to the end of February 2021. More detail about the interviewees can be found on page 14.

The Wessex RIS model operates virtually with a central multidisciplinary team coordinating patient care and reviewing test results that are undertaken at a local hospital of the patient's choice. The service communicates with patients (currently) via the phone from their first 'Welcome call' through to being told test results and their next steps. From referral to either onward referral or discharge from the service should be within 28 days.

Some initial feedback was given to the service after the first six interviews, resulting in a name change for the service[1], improvements to the patient leaflet and what is said at the 'Welcome Call'. From later interviews, it can be seen that these have improved patients' understanding and expectations of the service once they are in touch with the service.

This report provides a summary of the headline feedback and recommendations; before giving more detailed insight into each stage of the RIS, from referral to discharge.

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[1] From Rapid Diagnostic Service but people were saying they weren't getting a diagnosis. Just being told they do not have cancer.

Headline feedback

Summary

Overall, people were impressed with the RIS – its speed and the reassuring approach of the team are key factors in this. Whilst some would prefer to be seen face to face, people appreciate phone calls allow the service to work more quickly. They also find going to tests at their local hospital convenient.

> *"Flabbergasted about quick from referral to results under 4 weeks. So impressed with it. The nurses that ring were so lovely."*

> *"Can't fault it. My experience was really good. I wasn't upset or concerned. All my questions were answered."*

Two significant areas for improvement have been identified. Firstly, around the referral process; and secondly, when people are referred back to their GP on discharge. Further detail about these two points are set out below:

Referral process

This is a really key stage for patients and carers to build their confidence in the service, as well as giving them clarity about why they are being referred. Making sure the referral process is smooth helps prevent delays or distress for patients. The importance of recording people's access needs (e.g. information, transport and caring responsibilities) should be emphasised, as should explaining to patients what to expect from the service to alleviate any anxieties.

At the referral stage, GPs are not always making it clear that the RIS is to rule out cancer or how the service practically works. This lack of information means people expect the 'usual' NHS service – which people described as face to face, long waits have tests and get results back. It also means they are not being given contact details for the service. This means people do not know what practical steps they need to plan for, or how to contact the service if they have not heard from them or there is some other issue. This is especially the case if they are worried that they may have cancer.

"It was only after I spoke to the RIS did I understand. I expected to go to a hospital department and I looked online but couldn't see any information."

"I didn't know if I'd have to travel which would be difficult as I look after my Mum."

Results and next steps

No one we spoke had received a possible cancer diagnosis. Whilst being given the all clear from cancer was a relief, it does mean people are left not knowing what is wrong with them. For those who are referred to more tests, there is hope of an answer. But those referred back to their GP can be left worried about continuing unexplained symptoms and are not clear when and whether they should contact their GP, or whether the GP get in touch with them. Clarity is needed at discharge, particularly at present when patients are concerned about approaching health services unnecessarily.

"I'm not sure who will be following up. If I continue to have gut problems or weight loss, then I don't know what do to. What is first port of call?"

"I still feel weak and am still losing weight. I was advised to go back to the GP but it's very difficult in the pandemic."

Recommendations

For GPs

1. To strengthen GP practice awareness about the service, how it operates (including how to process initial tests) and what patients should plan for and expect

For the RIS

2. To ensure the 'Welcome Call' advises people about the types of questions they will be asked about their medical history

3. To ensure that calls with the RIS team check any accessibility issues (e.g. translations, other accessible formats, caring responsibilities, needing a carer's support, transport needs) to support people's specific needs

4. To clarify with patients when the RIS expect to be able to share scan results prior to tests taking place

5. To explore whether there is additional support that could be provided, by the service or GPs, around unexplained weight loss, particularly where this may be linked to stress

6. On discharge from the RIS, to be explicit with patients about whether they should proactively contact the GP or wait to be contacted

7. To date written summaries, not to use acronyms and provide clarity about what findings mean, including any implications for medication use

8. Review equality monitoring data for those using the service to ensure use of the service reflects the communities of Wessex

For hospital scanning teams

9. To share the interview feedback from individuals with the scanning teams (page 11 of this report) so that they can make any appropriate changes to their practice

Please note: Wessex Voices have also been reflected on the service evaluation process and next steps. Please see Appendix B for more information.

Detailed feedback

This part of the report provides detailed feedback from the qualitative interviews.

GP referral process

Whilst we did not specifically ask patients about their experience of getting a GP appointment, many people told us that they had had difficulties obtaining one; and most then accessed these services virtually because of Covid19. The issue of getting an appointment was frustrating, particularly because the interviewees have complex health issues or new, concerning, unexplained symptoms, and rely on GPs to help find answers to what is wrong and alleviate their worries.

For patients, the GP consultation provides a first impression and sets expectations of the service, what it is for and how it works, so is crucial to instil confidence and clarity for them. Only 12 of the 41 patients received a leaflet about the service – five from the GP, four from the service and it is unclear who provided the others. This may be because GP appointments are now mainly undertaken online so there is less chance of a GP handing out leaflets, but it means patients do not understand this relatively new speedy, virtual service.

Whilst some people said that were given enough information about the service, many said they were not told that the service was looking for suspected cancer or given any details about how the service works, just that the service would contact them shortly after the referral if they were ‘accepted’.

For those where the GP had not said that the service is looking for suspected cancer, it sometimes came as a ‘shock’ to then be told this in the initial RIS calls. For those who were told, some said that this was something they themselves were worried about and / or wanted to have this investigated and ruled out as a cause of their symptoms.

Many people were left wondering how the service worked and were under the impression it would be a ‘standard’ consultation at a hospital and did not expect to go through the RIS quickly as they did. This not knowing caused anxiety for some, particularly about how they would get to appointments or manage their caring responsibilities. It would have been helpful for them to understand that the service is virtual and that tests can be arranged locally.

Eight people who were interviewed said there were problems with the referral process. In addition, one person who declined an interview was very disappointed with the whole service from the referral on. Four of these people experienced problems with their filter tests and therefore delays. Three were not contacted for several weeks. Two were not given contact details for the service to be able to get in touch with them. Two were sent automated letters that were confusing and distressing because it was not clear who they were from or what they were about. Two did not even know they had been referred until the RIS contacted them.

Most people had been told that this was a new service so some were ‘forgiving’ of these types of issues and once they were in the RIS they couldn’t fault it. Over time it may be that GP practices will be more aware of the RIS and how it works to be able to provide better explanations, but for the next cohort of patients coming through this part of the process needs to be improved.

Initial phone calls with the RIS

People said the staff they spoke to during the ‘Welcome Call’ and the call to review their medical history were very polite, professional and helpful. Following changes to the script for the first call, patients now understand that the service is trying to rule out cancer.

These calls were thought to be thorough, and a few people mentioned the benefit of having someone with them to take notes and ask questions. One person with a sight impairment particularly highlighted the usefulness of this. One person suggested that people could be told in advance the types of questions that they would be asked about their medical history in the Welcome Call so they could come prepared. It can be distressing for people if they feel under pressure to remember the sequences of events or some of the details, especially when they have had many appointments or tests previously. A couple of people mentioned they were pleased that the team had had access to their full medical history.

Two people said they would prefer to see someone face to face or via video but most appreciated phone calls meant the service could work more efficiently. They recognised that it was also convenient for them too, as some pointed out, especially if they are already feeling unwell. A couple suggested having photos of the team on a website so people could look up who they were talking to.

It is clear that the RIS team need to systematically check people's specific support requirements, rather than relying on information on the GP referral form. In some cases, needs were picked up in the RIS calls but a few did not receive information in an accessible format as there was no record of their requirement for this. One person was not asked but knew how to arrange her own community transport to get to her tests; one arranged transport through their Covid 'bubble' but was worried about doing this; and one person struggled to find where the tests were in the hospital because she was not able to have her carer with her.

Having hospital tests organised and carried out

Most people were surprised at the speed at which their tests were organised and were pleased that this was the case. It is important that people expect this approach to testing as some people interpreted this as meaning the team already knew they had something seriously wrong with them, increasing their anxiety. They had expected things to move slowly 'as they usually do.'

Everyone had the tests at a hospital of their choice. They valued these being local as this was most convenient to them. Most said the experience was smooth and efficient and that the staff were nice.

A couple of people mentioned concerns about Covid safety precautions but only one said that they had debated whether to go or not. On balance they decided it was better to go sooner than wait. Because of Covid, some individuals made some suggestions that it may be helpful for scanning teams to reflect on:

- Provide clear instructions of the shortest route to the scanning suite or explain how far it is from the main entrance. This is particularly important because people cannot be escorted by carers at the moment
- Provide clearer instructions in the scan appointment letter about when and where to drink water in advance. Should this be at home or at the hospital and if the latter, is water provided (because of Covid restrictions)?
- Direct people to hand sanitiser immediately after their scan

A couple of more general points were:

- Always to introduce yourselves. We know this is particularly important for people with learning disabilities
- Provide a clear verbal explanation about having a cannula put in

A couple of people mentioned that they had asked the scanning team when they would get the results back. These teams were not able to give clear answers. Again, because people expect long waits this could be a cause of unnecessary anxiety, especially as the RIS is actually sharing them with patients quickly.

Calls about results and next steps

Everyone spoken to had had cancer ruled out so were clearly relieved at that. Where people were referred on for other tests, it was clear to them what the next steps would be. Some had been followed up with by different departments by the time we interviewed them a few weeks after their discharge from the RIS. Those who had not expected the ‘usual long waits’.

There were a cohort of people who were referred back to their GP. It is this group who were not clear about whether they should proactively follow up with the GP, or whether the GP will get in touch with them. This should be spelled out very clearly in the results and next steps call and on written summaries. Otherwise, people can be left concerned about continuing unexplained symptoms but not knowing whether to contact their GPs, when they understand the pressures GPs are already under and how frustrating it can be to get an appointment.

Written patient summaries

Thirty-one out of 41 people received their written summaries in a timely way. For five additional people their written summary had taken time to arrive. One person had waited eight weeks to receive theirs through the post. Even though the person had already received a call to go through their information in a timely way, they said if they had still been feeling poorly during those eight weeks it was too long to wait. Four people had not received a summary but for one of these their GP had. One person did not know whether they had received one. A few people did not know whether summaries are addressed to them or the GP.

Most found them to be clear. Some mentioned not understanding a few acronyms, some medical language or what the implications of certain findings were, including whether to continue taking their medication. People generally ‘Googled’ what they did not understand.

Some people mentioned that there were no dates on their summary. Some needed their summaries in large print but this was not provided as these needs were not identified by the GP or the service.

Other information and support

Most people did not feel that the service could have provided any other advice or information. This was probably because they felt very well supported by the team but also because they were not sure what was within the realm of possibility. One person did suggest that it would have been helpful to be offered physiotherapy for back pain.

Two issues that came up through the interviews were around mental health and unexplained weight loss. Sometimes people linked the two together – i.e. the weight loss may have been as a result of stress. On the former, people generally felt their emotional needs were explored and support was offered. Feedback was that dietary and stop smoking advice needs to sensitively tailored to individuals.

Overall comments about being looked after - from GP to RIS

On being asked overall how people felt they were looked after by their GP through to discharge from the RIS, many people repeated their concerns about access to GP appointments. They understand the pressures on GPs because of Covid but still found this frustrating. There were, however, a handful of GPs who were identified because of their determination to find an answer for patients.

> *“Can't fault any of them - from the RIS team to the local trust - the teams, nurses, consultants and doctors all brilliant. GP rang to see if she was ok and if I had any questions. They need a gold medal.”*

The interviewees went on to speak very highly of the RIS, often saying ‘you couldn’t fault it’. The things that they appreciated about the service were:

- Its speed and convenience
- That the team were are polite, professional, helpful and responsive

“a damn good team – great at working together”

- That people were given a thorough set of tests and checks
- Being telephoned when they were told that they would be
- Being told that they could call back with any future concerns. Several times people said “they made it sound like nothing was too much trouble” and this was very reassuring.

People we interviewed

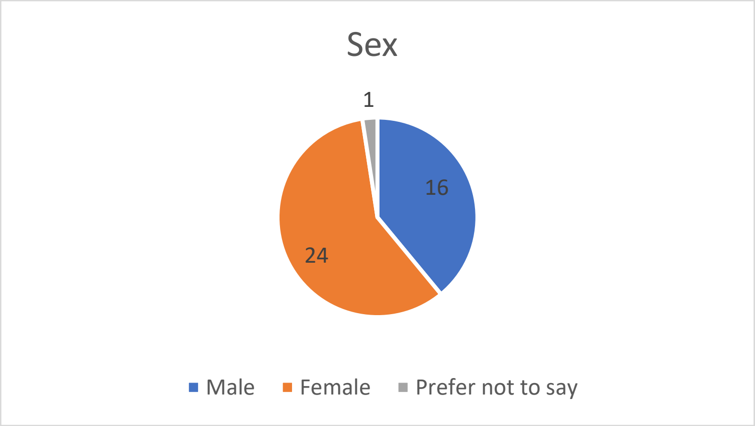
Of the 52 people who we could have interviewed, we were able to do full interviews with 41 people (40 patients and 1 carer). One person was interviewed with the help of their support worker.

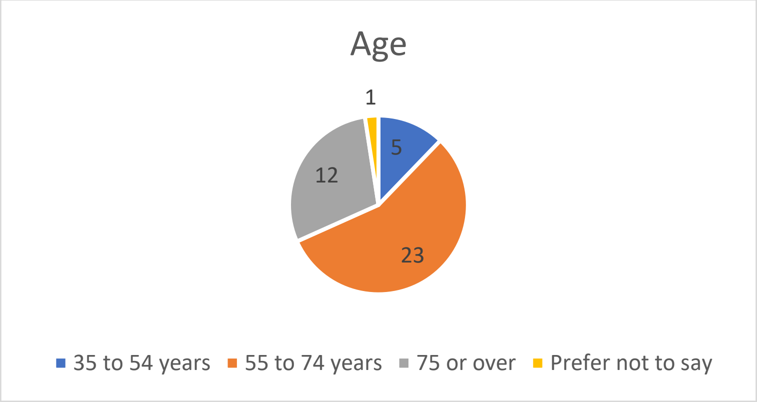
Five other people gave an overall comment about the service but did not want to do a full interview. Three of these comments were entirely positive. One was positive about the service but not the referral process. One was negative.

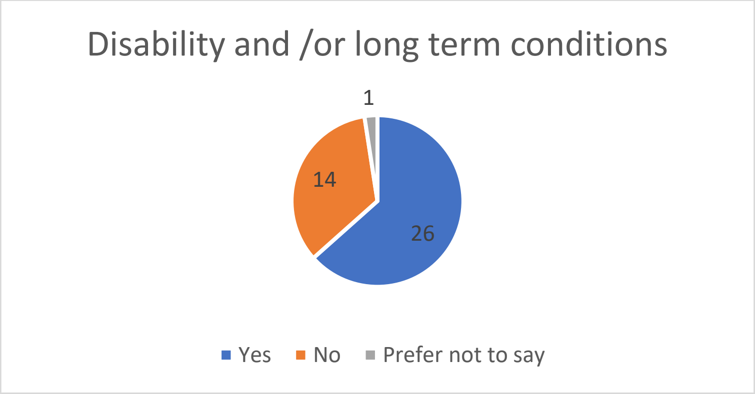
Three declined to be interviewed and we were unable to speak to four people after three attempts to contact them.

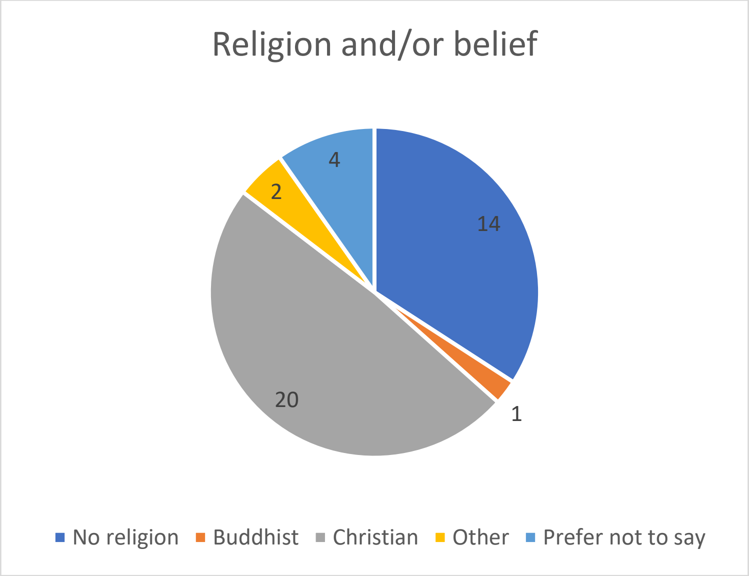
None of the people we spoke to had been told that they have a suspected cancer.

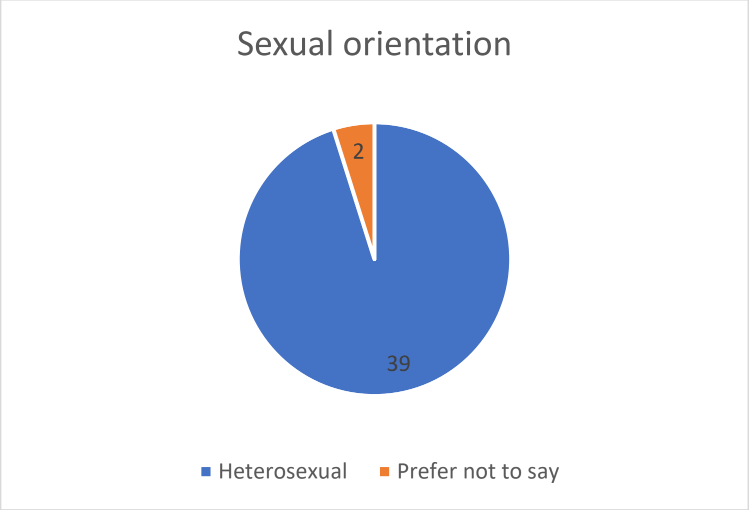
Interviewees' demographic data

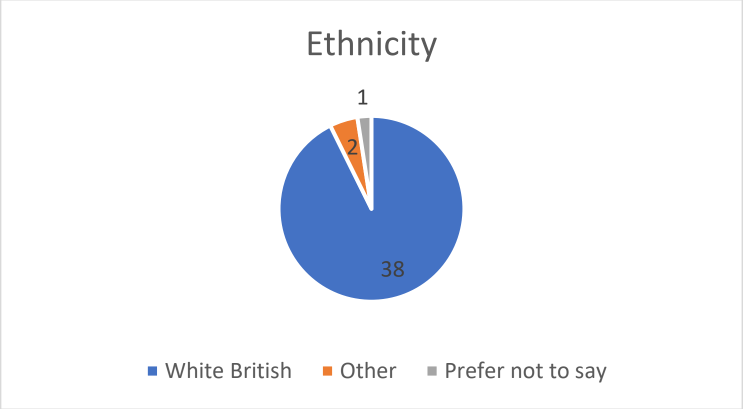



Age
1
5
12
23
35 to 54 years
55 to 74 years
75 or over
Prefer not to say


Disability and /or long term conditions
1
14
26
Yes
No
Prefer not to say


Religion and/or belief
4
2
14
20
1
No religion
Buddhist
Christian
Other
Prefer not to say





It is worth noting that this data should be reflective of those being referred into the service (unless there are groups of people with specific characteristics are declining their consent to be interviewed but we have not been made aware of this). If this is the case and as more people use the service, the RIS may wish to review their equality monitoring data for service use to ensure it is reflective of, for example, the Black, Asian and minority ethnic communities in Wessex.

Appendix A: Interview questions and process

The Rapid Investigation team asked people during their 'Welcome Call' whether they would consent to Wessex Voices contacting them to be interviewed once they were discharged from the service. The service sent a list of patients who had been discharged and consented to Wessex Voices each week to approach for an interview. Below shows the qualitative interview process:

Introduction

- Hello, my name is …
- I have been given your contact details by the Wessex RDS and would like to ask you about your recent experiences of this service.
- Confirm who talking to. Note if carer because patient unable to give feedback
- Reminder about who WV are
- The aim is to use your feedback to improve the service
- Everything you say will be feedback anonymously so you can't be identified
- Explain the structure of the survey and questions briefly
- Say roughly how long it will take / detailed because of new service
- Say you don't have to answer a question if you don't want to and you can stop or withdraw your consent at any time during the interview.
- Are you Ok to go ahead?

Key questions (although prompts were used to explore specifics)

1. When the GP referred you to the Rapid Diagnostic Service, what information were you given and did it explain why you were being referred?
2. Can you tell me about the experience of your first phone calls with the Rapid Diagnostic Service?
3. Can you tell me about your experience of having your tests organised?
4. After you had your tests, what did the Rapid Diagnostic Service tell you about what was going to happen?

5. Have you received a written summary from the Rapid Diagnostic Service yet? If yes, what did you think of it?
6. What other information and support did the Rapid Diagnostic Service give you?
7. Overall, how do you feel about how you were looked after by your GP and the Rapid Diagnostic Service team?

Finally a few questions about you …

These are completely optional and will help us see if we are providing a good level of service to everyone who uses the Rapid Diagnostic Service.

1. Which of these best describes how you think of yourself?

☐ Male
☐ Female
☐ Prefer to use another term – write in
☐ Prefer not to say

2. How old are you?

☐ Under 16
☐ 16-17
☐ 18-24
☐ 25-34
☐ 35-44
☐ 45-54
☐ 55-64
☐ 65-74
☐ 75-84
☐ 85 or over

3. Do you have any long-term physical or mental health conditions, disabilities or illnesses?

☐ Yes
☐ No

☐ I don’t know

☐ I would prefer not to say

If yes, please tell us more about your condition:

☐

4. How would you describe your ethnic origin?

A. White

☐ English/Welsh/Scottish/Northern Irish/British

☐ Irish

☐ Gypsy or Irish Traveller

☐ Any other White background

B. Mixed / multiple ethnic groups

☐ White and Black Caribbean

☐ White and Black African

☐ White and Asian

☐ Any other Mixed / multiple ethnic background

C. Asian / Asian British

☐ Indian

☐ Pakistani

☐ Bangladeshi

☐ Chinese

☐ Any other Asian background

D. Black / African / Caribbean / Black British

☐ African

☐ Caribbean

☐ Any other Black/African/Caribbean background

E. Other ethnic group

☐ Arab

☐ Any other ethnic group

☐ **Prefer not to say**

5. Which, if any, of the following best describes your religion?

☐ No religion
☐ Buddhist
☐ Christian (including Church of England, Catholic, Protestant, and other Christian denominations)
☐ Hindu
☐ Jewish
☐ Muslim
☐ Sikh
☐ Other
☐ Prefer not to say

6. Which of the following best describes how you think of yourself?

☐ Heterosexual or straight
☐ Gay or lesbian
☐ Bisexual
☐ Other
☐ Prefer not to say

End of call

- Thank you … without your feedback we can't change services for the better and it is important to shape services around peoples' experiences etc
- We will write up our findings into a report and share with the service. They are going to say that they have done as a result of what people have said. It will publish this (Wessex Voices and the Cancer Matters Wessex websites).
- End of call give contact details … if want to remove data or say anything else

Appendix B: Evaluation and engagement

Reflections on the interview process

The current interviews do not reflect the views of the following groups of people because of the small numbers of people accessing the service:

- People who have received a possible cancer diagnosis, particularly to test the experience of hearing bad news over the phone or via video
- Anyone who has accessed the service via video
- Carers to understand whether further support can be provided to them
- Black, Asian and minority ethnic people and those from the Lesbian, Gay, Bisexual and Transgender community

Next steps for the evaluation and engagement process

As number of referrals increases, we intend to use a quantitative approach, using an online / hard copy survey. This will enable us to continue to understand people's experiences. It is, however, proposed that we will continue to interview people who we are not hearing from, as identified above, to establish whether there are improvements that could be made for these groups.

IPOS Mori will also be undertaking an evaluation of these types of services across the country. Whilst the RIS and Wessex Voices have been feeding into the design of this evaluation we do not yet have the detail of how it will work or the questions that will be asked. We are however keeping an eye on how this develops so we can align it with our approach.

We are also continuing to engage with people who may find it more difficult to access this virtual service and specifically plan to listen to the views of people with learning disabilities and their carers; Deaf people; and those who already experience anxiety. The findings will be brought to future RIS meetings.

Contact details

For more information about this report please contact Sue Newell at Wessex Voices on sue.newell@helpandcare.org.uk or 0759 4241898.