

National Survey for Wales 2022-23 Topic Request Form

Before you complete the form, **please read the following checklist to make sure that the National Survey for Wales will best serve your needs.** We will prioritise questions based on these criteria.

Key criteria:

1. Will the results influence decision making?
2. Is adequate information not available elsewhere?

If you fulfil these criteria please consider the following.

What works on the telephone survey?

Topics where...

- you need to have an accurate figure, rather than a rough indication;
- you want to make sure that the results cover everyone, including for example people who are not on the internet or are harder to reach;
- the topic is already fairly well-understood, and you have a good idea of what you need to know;
- you want to analyse results in detail, using other answers on the survey (cross analysis).

What doesn't work so well on the telephone survey?

- Hypothetical questions or questions looking forwards / backwards in time e.g. how will you feel about something next week, or in a months' time, or how you felt about something in the past.
- Anything for which you need answers very quickly – results will be available in the summer of 2023.
- Understanding detailed or complex issues that require many questions or for people to think carefully (e.g. they haven't thought about the topic before). In this instance, a bespoke survey or qualitative research may be more suitable.
- Topics where people in institutional accommodation (e.g. care homes or prisons) are of particular interest.

If you are unsure at all about your request and whether it is suitable, please contact **official 1 (REDACTED – SECTION 40)** to discuss before completing this form.

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1 Contact details

Name	Email	Phone number	Role
Your details			
Official 2 (REDACTED – SECTION 40)	Official 2 (REDACTED – SECTION 40)	(REDACTED – SECTION 40)	(REDACTED – SECTION 40)
Person responsible for request on a day-to-day basis (leave blank if same as above)			
Person responsible for signing off this request			
Official 2 (REDACTED – SECTION 40)	Official 2 (REDACTED – SECTION 40)	(REDACTED – SECTION 40)	(REDACTED – SECTION 40)

2 Title of topic (e.g. wellbeing, internet use, satisfaction with health services)

Data Promise - use of citizens health and care data

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3 What would you like to find out?

<p>Brief overview of background/context to this topic, including if it is a repeat topic (asked previously on the National Survey.)</p>	<p>The Digital Strategy for Wales and Strategic approach to social care data in Wales both discuss the need to improve the use of data and sharing of data within health and care. They also emphasise the need to have a ‘discussion with the public’ to</p> <ul style="list-style-type: none"> • understand their views about the use of data in health and care • address any concerns or worries they may have about the use of their data • inform them about how data about them is being used • assure them that their health and care data is being treated responsibly, handled securely and used ethically <p>There is a commitment to develop a “data promise” for health and care, which assures citizens about how their health and care data is being held and used.</p>
<p>What evidence gaps do you want the survey to fill?</p>	<p>We want to understand people’s views about the use of data in health and care and find out what they think <i>is</i> and what <i>should</i> be done with their data and what shouldn’t.</p> <p>We will be commissioning qualitative research into people’s views about the data promise and use of their health and care data, however, we’d like to have some representative quantitative data to support the communication around the ‘Data Promise’.</p> <p>We are also contemplating offering an opt-out, so that people could opt out of their GP records leaving their GP, (not for direct care purposes, but for planning health services and research purposes) - we’d like to know whether that would have a high take up or not.</p> <p>This information could also help us develop the messaging around the Data Promise as well as evaluate the effectiveness of the ‘Data Promise’, by providing statistics about attitudes to data sharing, before the launch of the ‘Data Promise’.</p>

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<p>What would you like to find out? If you would like to request specific survey questions, please include them here. E.g.</p> <ul style="list-style-type: none">• Whether person is a smoker• Whether person uses e-cigarettes• Whether person knows where to look for support in relation stopping smoking.	<p>I would envisage a series of questions, along the lines of:</p> <p>The Welsh Government and NHS Wales would like to make better use of health and care data in Wales to help and plan for Wales's health and care needs. To what extent do you agree or disagree with the following statements:</p> <ul style="list-style-type: none">• I trust the NHS in Wales to keep my health records safe• I'd be happy for my health records to be shared with Social Care services to help plan my care• I'm happy for my health and care records to be shared within the health and care service to plan my own treatment or care• I'm happy for my health and care records to be shared within the health and care service to help respond to a major public health issue like an epidemic• I'm happy for my health and care records to be shared within the service so that the NHS has better information to plan health services• I'm happy for my health records to be shared within the service to develop knowledge about the uptake of vital medicines and vaccines.• I'm happy for my health and care records to be shared within the health and care services to research into treatments for particular illnesses• I'd like to be able to view my own health and care record on-line <p>Or if you were planning to include questions on hospitals, similar questions could be grouped with questions like HspKnewInf - At the start of the appointment, the health professional knew all the relevant information about me and my medical history.</p>
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4 Why do you need this information and how will the results be used?

<p>Will the results feed into any policy/delivery decisions?</p> <p>Please give details of:</p> <ol style="list-style-type: none"> 1. Which decisions; 2. How the results will influence these decisions; and 3. When the decisions need to be made. <p>This is key to deciding whether a topic is included again.</p>	<p>The results will help shape the message and communication of the Data Promise.</p> <p>For example, if we found that a high proportion of people did not agree that their health data should be shared within health and care for certain reasons, we could improve the communication around that or offer an opportunity to opt out of that data sharing.</p> <p>We hope to ‘consult’ on the data promise policy towards the end of this year, and launch sometime in 2022, however, the ‘Data Promise’ is a clear statement of what we will do or not do with people’s data, but as part of that work there are a number of ‘enabling activities’ (i.e. legislation to reduce barriers to data sharing) which will take longer to change and so some of the data sharing activities will follow in the years to follow. The statistics about public attitudes will help with decisions about how to share data (with consent or not) and the communication around the data promise (i.e. website, FAQ’s etc.)</p>
<p>If this is a repeat topic, please provide details of how previous results have been used, and why you need to include them again.</p>	<p>Not a repeat topic.</p>

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<p>Will the results support actions / themes in Prosperity for All or the Well-being of Future Generations Act? If so, please give details.</p>	<p>Prosperity for All Healthy and Active – In order to safeguard the health service and meet its wider responsibility for health improvement, we need to increase the pace of innovation and integration. We must “work with NHS Wales to provide people with digital ways of accessing health and care services and information, helping empower patients and carers to take greater control of their health and wellbeing”</p> <p>Well-being of Future Generations Act A Healthier Wales 4: Seamless, preventative organisations and services Share and use data between public services - Better sharing of data to improve the health and wellbeing</p>
<p>Will the results be used to monitor Welsh Government performance? Will performance be compared with other countries?</p>	<p>Not to monitor ‘performance’, but to provide insight into people’s views about data sharing. This could provide a baseline to monitor any change in attitudes over time.</p>
<p>Will the results be used outside Welsh Government?</p>	<p>Yes, by Digital Health and Care Wales and health boards</p>

5 Are there any other data sources available?

Are there any other surveys or administrative data sources which cover similar topics? If so, please give details of the sources and how including the topic in the National Survey would add to this existing information. (The relevant team in Knowledge and Analytical Services may be able to help you identify any existing sources – please let me know if you need contact details).

<p>There are a number of qualitative studies around the use of health data, and some data sources (e.g. YouGov) on public views on data ethics but the questions are</p>
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not quite what we are looking for and the National Survey would provide a more representative sample.

6 Group of interest

Do you intend for the questions to be asked of everyone taking part in the survey, or of specific groups? Examples could include:

- Specific age groups
- Users of a particular service
- Specific geographical areas

If we can ask some or all of the questions on a topic only of particular groups, there is more chance we can fit the topic in.

We would like to ask the questions of all adults, but it will be interesting to understand whether people of certain ages, who use health services more regularly (have an illness or are carers) have different views about the use of health and care data.

7 Geographical level of analysis

At what geographical level would you like to see the results broken down?

If the results are only needed at national level, there is more chance we can fit the topic in because it can be asked of fewer people.

National	Y
Regional (e.g. N / Mid / SE / SW Wales)	N
Local authority	N
Local health board	N
Other (please give details)	N

Please explain why it is important to analyse the results at this geographical level. What would be the impact if results were only available at a higher level?

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8 Change over time

Would you like to see how the results change over time? If so, why is this important?

Yes. In order to assess any change in public confidence in the use of their personal data over time, so that we can assess the impact of future interventions.