

crohn's and
colitis
UK



Inform
Support
Research

IBD PATIENT PANELS

IBD Patient Panel Surveys

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Why Carry Out a Survey?

- Bring about improvements in part of a service that you think may not up to standard (Diet in hospital)
- Strengthen your case for improvements in part of a service that you know is not up to standard (East Kent Patient Access to Services Survey)
- Get information from members of the IBD population that is not represented on your Panel (younger people, ethnic minority groups – eg Leicester)

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Where to begin?

- Be sure of your aims (what do you want to get out of it?)
- Have a very clear focus - set parameters on the scope
- Work with your allies – not in isolation you – you will need some professional ownership
- Find out what other people have done in the same field
- Set up a planning group – with some expertise on it
- Write down why you are doing the survey. This will be included in the Survey Report

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Methodology (what you are going to do and the way that you are going to do it)

- This will be dictated by the resources that are available to you
- Compromises will always have to be made – ‘good enough’ principle
- Understand the difference between quantitative and qualitative approaches. You will almost certainly be doing the latter
- Keep your questionnaire short - there is a correlation between compliance and length of questionnaire
- It is better to run two surveys rather than try to cover a range of topics
- Pilot it on a friend

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Some sample questions

- How long have you been diagnosed with IBD?**

Would this question be better if it asked *when did you last use NHS services in connection with their illness* rather than how long they have had it? ie How relevant are their comments to the NHS service that is being provided today

- Are you currently unwell or in a period of remission?**

What can you do with the answers to this question? This is an example of gathering information that you probably don't need

How do you score a response?

An even number of tick boxes or an odd number?

Use a scale of satisfaction including a smiley at either end -



much clearer where to put your tick on your scale of satisfaction

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Some sample questions –

Open ended

•Have you any comments to make regarding your treatment or the services available to you?

This open ended question is possibly the most important question in the whole of your survey. It gives the person completing the questions the opportunity to answer in an undirected way and can bring rich pickings in terms of qualitative data.

•Please state 2 things which were good about the service you have received

•Please state two things which would have improved the service you have received

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Methodology (cont...)

- How will you propose to distribute it?
- What is the target number of responses? Don't get too few ...or too many! (100?) and typically you should expect only one third response rate
- If it is being sent to Patients in hospital or using a hospital database then you may need Ethics of Research Committee approval for your methodology and your questionnaire
- How is the questionnaire going to be returned?
- Remember confidentiality is important. You have a responsibility to ensure responses are anonymised

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The Survey Report

- Who is going to collate the responses and produce the report?
- Any cross tabulation? Hopefully not!
- Send the report out in draft first – you may have got something wrong!
- Try and make the report look professional
- Include in the report an Action Plan - areas which you suggest might be improved and how
- Remember the difference between influencing and controlling - you can only offer suggestions for improvement

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The Survey Report:-

1. Background

2. Methodology

3. Results

4. Conclusions

5. Action Plan

6. Appendices

a. Covering Letter

b. Survey Form

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The Survey Report (cont...)

- Think who you are going to send the final report to....
- Offer to meet and discuss with key individuals or invite them to your Panel Meeting
- Don't be surprised if your report is challenged on the grounds of validity, non representativeness, insufficient sample size etc (if someone doesn't like your findings this will be their first line of attack!)
- Do reflect on your work and make it better next time – Continuous Improvement!

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