CANASSESS:PC

Results from the CANASSESS study

A study developed in Yorkshire and funded by Yorkshire Cancer Research

University of Hull

WE ARE MACMILLAN. CANCER SUPPORT

yorkshire cancer research

HULL YORK MEDICAL SCHOOL

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Meet the Team

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Why did we do the study?

Improving Care for Cancer Patients

Cancer patients and their carers often have problems related to cancer that they need more help with. Our research aims to test whether a new cancer needs assessment tool to help GPs and practice nurses improves care and support for cancer patients and their family carers. However, before we can do this big study, we need to see if this possible.

To support a larger study

The CANASSESS study aimed to see if a larger study (CANASSESS2) with more GP practices, patients and carers was possible to run. The study tested the use of a tool by GPs and nurses to help them assess patients' needs. We needed to know if GPs and patients would take part, how a larger scale study should run, if patients/carers found the questionnaires meaningful and useful and if there was anything else we needed to do to improve the study design for CANASSESS2.

What was the study about?

Who took part?

- 47 Cancer Patients in Hull
- 17 Carers
- 11 doctors, nurses and research support staff from four GP practices in and around Hull

How did we recruit?

The research team asked GPs in and around Hull if they would be interested in taking part. The GPs who said yes contacted their cancer patients to ask them if they would like to be involved. Anyone who was interested then volunteered to take part.

Hull Skyline

Thank you to collaborators

We would like to thank all of our collaborators who helped make the study possible including;

Dr Victoria Allgar, Senior Lecturer in Medical Statistics, University of Hull

Dr Andrew Taylor, Research Excellence Manager, University of Hull

Prof Una Macleod, Hull York Medical School, University of Hull

Prof Amanda Farrin, Professor of Clinical Trials & Evaluation of Complex Interventions, University of Leeds

Dr David Meads, Associate Professor in Health Economics, University of Leeds

Ms Alexandra Wright-Hughes, Senior Medical Statistician, University of Leeds

Prof John Blenkinsopp, Professor of Organisational Behaviour, Northumbria University

Prof Robbie Foy, Professor of Primary Care, University of Leeds

Prof Hamish Fraser, Professor of eHealth, University of Leeds

Thank you

We would like to take the opportunity to thank all of our participants. We are grateful to the GPs practices learning about the tool and to the patients and carers for taking the time to do the questionnaires, go to an appointment and those who agreed to an interview. The time and effort everyone has put in will enable us to carry out CANASSES2 and test the best way for GP practices to look after their cancer patients and their carers.

How did the participants help?

Patients and Carers

Patients and carers who took part in the study met with one of the researchers and filled out questionnaires about their experiences of cancer and any unsolved problems they might have. Patients were then asked to meet with their GP for a needs assessment appointment. The GP practices had been provided training to use the new needs assessment tool which they could use for this appointment. Patients and carers then completed the same study questionnaires again at 1, 3 and 6 months.

Some patients/carers also took part in an interview about their experience of the study. Patients and carers were asked about how they felt about their current care, their GPs' involvement in their care since their diagnosis and their views on the study questionnaires. Finally they asked patients/carers what they thought about the needs assessment appointment with their GPs compared with usual care.

GPs and Clinicians

GPs and research support staff were asked to use the tool at the needs assessment appointment. The practice groups were asked how they found using the tool and how they experienced taking part in the study with the patients.

What did we do with the information?

Researchers analysed responses to the study questionnaires to look at how responses changed over time, and whether the questionnaires had been completed.

Researchers analysed the interview responses by looking for any concerns people may have had about the study and any comments about what worked well.

Overall, we were trying to find out whether it was worth doing a much larger study. Large studies are expensive and take a long time. It is therefore important to know if a bigger study is worthwhile and likely to be completed successfully.

Hull University Sculptures

What are we doing next?

CANASSESS2

CANASSESS1 showed us that we can do the larger study and Yorkshire Cancer Research have agreed to fund it.

The larger study called CANASSESS2 will be carried out across the whole of Yorkshire and the North East of England, in 1,080 patients from 54 GP practices. It will be able to test if routine use of the tool by GPs and nurses improves patients' (and their carers') experience and by how much.

CANASSESS2, if it proves that the tool is effective, will set the new standard of care across not only Yorkshire, but across the whole of the UK, improving the experience of people with cancer and their families across the country.

The help that we have had from the GP practices, patients and carers in CANASSESS1 has been crucial. We have learnt vital information that will allow us to carry out CANASSES2 as efficiently as possible.

We wouldn't be at this stage without our CANASSESS1 participants!

Final Thoughts and Improvements

Our participants have helped us think of improvements for the next study including:

1. Give more information about the study to patients and carers
   -Make sure it is clear who should be making the appointments
   -Make sure everyone is clear about what the study involves

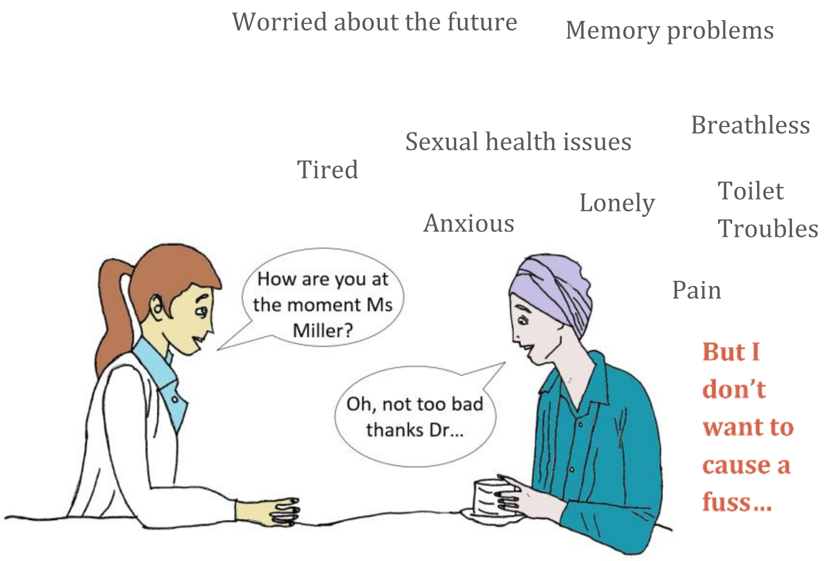
2. Give more training to clinicians and GP practices involved in the study
   -Make sure it is clear who should be making the appointments
   -Get as many people involved in the practice as possible

3. Refine the questionnaires
   -Decide which is the most useful questionnaire for the patients and carers to fill out
   -Change the healthcare use questionnaire because it's too complicated!

4. Change some of the timings of the study
   -Speak to patients and carers more quickly after the appointments and questionnaires

Why a new approach is needed

It's a funny thing about people…



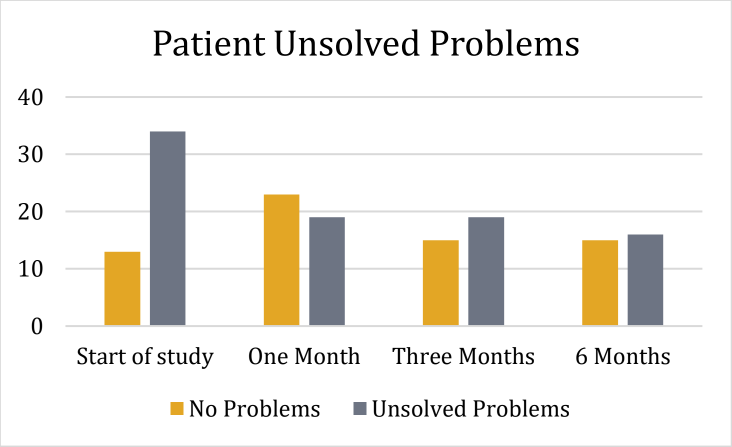
We tend not to tell people what our problems are unless we are asked, 'what's wrong?'

The tool used by the GPs in the study was a one-page guide which helped GPs to ask the right questions. The questionnaires and interviews were carried out to test if the tool was useful and to make any improvements for the larger study (CANASSESS2).

What did we find out?

Questionnaires

As well as testing the tool we wanted to find out how well the questionnaires worked and which one was best to use for CANASSESS2. The patient and carer responses helped us to learn lessons for CANASSESS2.



The chart shows that at the start of the study nearly three-quarters (72%) of patients had unsolved problems.

After 1 month the proportion of patients with unsolved problems had reduced to just over half (54.8%)

Carers filled out questionnaires as well and their unsolved problems were also reducing as the study continued.

What did the GPs and nurses think?

The clinicians found that some of their staff needed more training about the study:

> *“there’s a high turnover of receptionists, … so often you’d get a new receptionist would come in and they’d, … put them in with a non-CANASSESS trained GP for a ten minute appointment...”*

Some GPs liked the tool so much they are still using it in appointments even though the study is finished.

An important finding from talking to patients and clinicians was that some misunderstood palliative care as only being for patients in the last few days and weeks of life. Clearer information about palliative care – that it also helps people live as well as possible even if they are still having active treatment - would help improve this.

> *“I had to read it a coupla times, but no, it was; the hospital, hospice and palliative care. I thought no, don’t want that, I don’t need that. I’m not having that (laughs) not yet.”*

What did people think of the study?

Patients and carers generally found taking part in the study a positive experience. Many found study appointments useful and that the questionnaires gave them an opportunity to reflect on their needs and their use of their GP and cancer services.

> *"It makes me think more about how I really do feel, cos you can soon pass that straight over your head, oh I'm feeling all right. It makes you think are you really feeling like that today, or aren't yah, or are you OK?*

There was confusion about some parts of the study from patients and clinicians regarding who should be making the appointments with the GPs to try out the tool (it seems the researchers were not always clear!).

> *"Well I was told by yourself that I, that I, after you came down and saw me, that I need to make the appointment. So I went and made the appointment and then they said, no, we're gonna contact you."*

Why might the tool help?

The appointments with the tool allowed patients to talk about their problems and the GPs to be aware of the areas they wanted help with.

Patients and carers benefitted from talking to their GP and the study gave them a reason to see them. It is possible that the appointment itself, rather than the tool, was the helpful thing, or that things might have got better anyway over time. Just filling out the questionnaires may have been helpful.

Therefore, we cannot be totally sure from CANASSESS1, if the improvement we saw was from the tool or the other reasons. The larger trial, CANASSESS2, will be the one which <u>can</u> answer that question.

What did the patients think?

Current Care

We found that most patients were happy with their current care even though they had unsolved problems (as seen from the questionnaires). Some were not sure if they should see their GP or the cancer hospital for help for different problems. Many patients hesitated to see their GPs about their cancer and felt that communication between hospital and GP services should be better.

> *"The care, the care's been OK, but fundamentally the care's not come from my GP, the care's come from oncology department, from the Queen's Centre, Castle Hill, not come directly from my doctor"*

Most patients expressed this opinion in the interviews:

> *"But it, it's like, you know, if, as I say, with the allergy that kicked off, I went to see the GP, I did mention it at the hospital and they, and, you know, they said see yer GP (laughs) so. So it's like there's that split really"*

Timing

Many patients and carers said that they needed more information about their cancer and the support available to them at various times, as well as ongoing information after being diagnosed. Some patients got a phone call from their GP to 'check in' after they were first diagnosed. This helped people feel 'looked after'. However, most patients dealt only with the cancer hospital. Similarly, some patients preferred to see their usual GP but at times had to see whichever GP was available.

> *"But I don't, I don't think the doctor like called us in to talk about it or we got any information from the doctors at all, do you?*
>
> *"I'd been diagnosed with cancer and we didn't know what to do, where to go and, and things like that."*

Patients wanted ongoing information and support especially after treatment finished and oncology was no longer involved.

> *"So I, I just think it's, it's important that professionals understand a cancer patient will always be a cancer patient"*