

SHARED INTELLIGENCE



BENEFITS MADE CLEAR IN HEALTH CARE SETTINGS

SCOPING RESEARCH | FEBRUARY 2011

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I EXECUTIVE SUMMARY

Purpose of study

1. Macmillan commissioned Shared Intelligence to carry out a scoping study into the introduction of the Benefits Made Clear (BMC) online tool into health care settings. This research focuses on the application in the Macmillan Information and Support Centres in hospitals.
2. Macmillan has found that 91% of households affected by cancer suffer loss of income or increased costs as a direct result of cancer. In response Macmillan (with support from Department of Health's National Cancer Survivorship Initiative) have developed a range of benefits-related support services for people affected by cancer (PABC). These include a national Benefits Helpline, a number of local specialist Benefits Advisors and now the BMC online tool which allows users to explore their eligibility for five specific benefits pathways.
3. The tool, which went live in December 2009, is not intended as a substitute for detailed benefits advice but was specifically designed to enable people affected by cancer to access a source of information at times convenient to them.
4. The purpose of the study was to allow Macmillan to understand how well the BMC tool could reach its intended audience, how it can add most value and how any challenges to implementation can be overcome. Therefore the scoping study was designed to identify the opportunities and practical challenges associated with piloting BMC in the wide range of Information and Support Centres in Hospitals around the country.

Methodology

5. The research involved an integrated programme of participative consultation:
 - An Experts' Workshop with six key Macmillan staff.
 - Ten phone interviews with patient-facing staff in a range of hospital settings.
 - Site visits to five Information and Support Centres located in hospitals around England. The site visits involved interviews and discussion groups with 50 stakeholders in total – including Centre Managers, Benefits Advisors, cancer nurses, volunteers and PABC.
 - Research focused on two groups of factors – perceptions and attitudes on the one hand; and practical implications on the other.

Findings - Perceptions and Attitudes

6. Across the five sites it was quite clear from the research that the different groups of consultees had generally consistent views, irrespective of the Centre with which they were involved although there were significant differences between the different groupings of consultee. Broadly, PABC were the most positive about the initiative while Centre Managers and Benefits Advisors had most concerns about the introduction of the BMC tool into Information and Support Centres.
7. PABC generally welcomed the idea saying it offered more choice and increased anonymity and privacy. It might even help overcome the barriers and stigma some people had regarding claiming benefits. They discussed the need for support but generally believed this would not be a problem, even if the 'hand holding' came from volunteers rather than Centre staff. However it was recognised that an online tool would not suit everyone. It was agreed that an early introduction to the tool would be most useful – early after diagnosis but before treatment starts – and also that access to the tool should be ongoing.
8. Cancer nurses tended to confirm the views of PABC and all said they were willing to refer their patients to the tool. They appreciated the initiative whilst expressing the view that a supported approach could particularly help older people and that the BMC tool could be an effective service to encourage people into the Centres.
9. Volunteers were broadly supportive of the tool and willing to be trained but Centre Managers tended to be more wary of the pressures on their own time and that of their volunteers if users of the tool needed considerable assistance and monitoring. Some Centre Managers were also yet to be convinced about the effectiveness of the BMC tool compared with other benefits advice methods.
10. Overall, Benefits Advisors felt the tool had a number of limitations and that it would still be necessary to have face-to-face sessions with users to confirm details, and ensure accuracy and interpretation.

Findings – Practical Implications

11. The context of each Centre varies in terms of budgets, staffing and volunteer resources and availability of IT equipment. The practical issues included:
12. Privacy and Confidentiality – The need for appropriate private spaces and the implications of this for staff deployment between public and private spaces; and the audio element of the tool as a potential problem for privacy.
13. NHS Policies on Hygiene and IT – The use of headphones would be a solution to the audio element but the use of shared media equipment contravenes some NHS Trust hygiene policies. Some Trusts also have 'guided use' policies regarding the use of IT equipment by members of the public, whereby a

- member of staff or volunteer has to monitor the user, with obvious implications for staff or volunteer time.
14. Training – It was generally accepted that anyone supporting PABC to use the tool should have a certain level of skills and knowledge and that ‘train the trainer’ was the most appropriate way of achieving this standard.
 15. Volunteers – Their role was highlighted as vital for the effective use of the BMC tool in Centres. Volunteers generally expressed a willingness to be trained to use the tool but some Centre Managers felt some volunteers would not be willing or able to take on this role – therefore some specialism may be required.
 16. Promotion – It was agreed that the introduction of BMC should be supported by a range of promotion methods to raise awareness – including leaflets and smaller ‘business cards’, posters, a high profile ‘BMC kiosk’, case studies and getting the message out to networks and patients groups who don’t currently use the Centres.
 17. Referrals – Professionals have a key role in increasing access to the tool and to the Centres in general. Cancer nurses were currently the most likely to refer PABC to the tool and to explain its purpose. Centre Managers were more reluctant to refer to the tool in its current form but felt that if they from Macmillan received greater clarity on the tool’s purpose and value added they would be more committed to making it happen.

Recommendations

18. The paper makes a number of recommendations based on evidence gathered during the study.
19. Generally it is accepted that the BMC tool will work for some but not for others – and that any piloting of the tool needs to be nuanced to the particular circumstances and needs of each Information and Support Centre.
20. Training – This should be aimed at Centre Managers who will then cascade knowledge and skills down to volunteers and others. It should be light-touch and aimed at giving Centre Managers an understanding of the purpose of the tool and a working knowledge of its use.
21. Guided use IT policies – Macmillan should support Centre Managers to negotiate with Trusts where difficulties are being experienced – and consider the business case for alternative approaches where that is not possible, such as CD ROMs.
22. Promotion – A business card-style document should be developed showing the range of benefits-related support and how each can be accessed. Where possible, the need for lengthy new literature should be avoided but information about BMC should be incorporated into existing materials.

23. Referral – Contact with health professionals should be used to build on their willingness to act as advocates for the tool. Consider the idea of a ‘champion’ within each Trust to spread the word about BMC.
24. Communications campaign – It is clear that Centre Managers and Benefits Advisors remain uncertain about the value of the tool, therefore it makes sense to focus communications activity on reassuring and convincing these vital groups of the value of the tool and achieving their buy-in regarding its introduction. A number of detailed recommendations are made for the approach to and content of a communications campaign aimed at Centre Managers and Benefits Advisors.

1. INTRODUCTION

- 1.1. Macmillan commissioned Shared Intelligence as part of the National Cancer Survivorship Initiative (NCSI) to carry out a scoping study into the introduction of the Benefits Made Clear (BMC) online tool into health care settings.
- 1.2. Macmillan has found that 91% of households affected by cancer suffer loss of income or increased costs as a direct result of cancer. In response Macmillan have invested in local provision of benefits advice and a national benefits advice helpline to offer specialist benefits advice to people affected by cancer (PABC). In addition to this, Macmillan developed the BMC tool. This offered online access to an interactive tool that allowed PABC to explore their eligibility for five benefits pathways.
- 1.3. To date, the tool has been used by 30,000 people. A usability study was completed in Summer 2009 which recommended changes to be implemented, and these are currently being undertaken.
- 1.4. Macmillan recognised that there was an opportunity to improve the reach, impact and exposure of the tool through introduction into Information and Support Centres within health care settings, such as hospitals. It was seen as having potential to increase the reach of the tool by making it available to PABC who might not have the internet at home, or may not be able to navigate the site without support.
- 1.5. In particular, it was felt that this setting might encourage PABC to access welfare information at an early stage of their treatment, as it could be accessed whilst a PABC was attending treatment at their hospital. The relatively private environment provided by Information and Support Centres was a key reason why this particular health care setting was identified.
- 1.6. Macmillan wished to understand where and how the tool could add most value, and how challenges to implementation could be overcome. Each Information and Support centre was considered unique, with differing levels of resources and different facilities. Therefore scoping research was intended to identify potential opportunities and pitfalls of introducing the tool into these different settings.
- 1.7. Key research questions as outlined in the brief focused on:
 - Where should the tool be located to add most value?
 - How can the tool complement existing services?
 - How can PABC be made aware of the tool?
 - What groups will be accessing the tool in the centre, and why?
 - What support will PABC require in using the tool?
 - What are the main challenges posed by introducing the tool into health care settings?

- What are the practical implications for Macmillan and its partners?

Methodology

1.8. We began our research in mid January 2011, and it was completed in the second week of February 2011. The research comprised the following three activities.

- **An Experts’ Workshop** was conducted with six information and financial support experts from within Macmillan. This explored existing ideas about how the tool might be coupled with a health care setting, identified the key issues, and how the research should address these.
- **Site visits** were carried out at five Information and Support Centres located within hospitals in Derby, Macclesfield, Wythenshawe (Manchester), Middlesbrough and London. Centre Managers at all sites were aware of the tool however none already offered access to it. During visits our research team interviewed staff such as Centre Managers and other Information Specialists; benefits advisors who served the centre; volunteers; Cancer Nurse Specialists and other patient-facing specialists; and held discussion groups with people affected by cancer. Our interviews were with a mixture of people who had and had not accessed the tool themselves, however all interviewees were shown screen shots of the tool, and talked through how it worked.

Spread of Interviews by site					
SITE	Centre Staff	Benefits Advisors	Volunteers	People Affected by Cancer	Cancer Nurses and other specialists
Derby	2	1	1	3	2
Macclesfield	2	0	0	5	6
Wythenshawe	2	2*	2	4	2
Middlesbrough	2	1	3	3	0
London	1	1	1	3	1
TOTAL	9	5	7	18	11

*Inc 1 'Jobs Advisor'

- **Semi-structured telephone interviews** were conducted with ten additional contacts. These comprised six centre managers, two cancer network administrators, one benefits expert, and one Cancer Nurse Specialist.

Acknowledgements

1.9. Our thanks go to all those who facilitated the study particularly the Centre Manager and staff, Benefits Advisors, cancer nurses, volunteers and PABC at the following hospitals for their help in organising and participating in our research visits.

- Derby Royal Hospital;
- Macclesfield District General Hospital;
- Wythenshawe Hospital (Manchester);
- James Cook University Hospital (Middlesbrough);
- Kings College Hospital (London).

1.10. The research team would also like to thank the individuals who gave their time to participate in our research through telephone interviews and participants in the Macmillan Experts' workshop.

2. FINDINGS

- 2.1. Research focused on two groups of factors that could inform or affect the setting up of a pilot or wider roll-out of the Benefits Made Clear tool in Macmillan Information and Support Centres. These were perceptions and attitudes, and practical implications. This section deals firstly with the key findings relating to the perceptions and attitudes of those interviewed to the idea of the tool being made available in a centre. Secondly it sets out key findings regarding the practical considerations of piloting the tool in a centre.

Perceptions and Attitudes

- 2.2. Typical attitudes of the different groups could be identified, with clear attitudes of each group being generally consistent across the five sites visited. However, these groups of views were very different, and can be ranked in terms of their positivity about the tool in a health care setting.



People affected by Cancer

- 2.3. Of the 18 PABC who took part in our research, eight had used the tool prior to the discussion; these PABC attended the focus groups in Macclesfield and Wythenshawe.
- 2.4. At most sites PABC welcomed the idea that the tool offered them another service and further **choice in how they accessed benefits advice**. However they all recognised that it would suit some and not others.
- 2.5. Having the tool available in the centre appealed to them for a number of reasons. Some thought that it could offer **anonymity** in some situations. One example was a carer who thought being able to access the tool in the centre whilst her husband was receiving treatment offered greater privacy and allowed her to deal with this practical matter without worrying her husband. Similarly, another PABC who only had access to a computer at her son's house felt more comfortable accessing information away from her family, who she felt would be unduly worried.

"I would still rather come here, even though my daughter has computer access. Don't want them to know I'm looking

for benefits advice; I want to do it with someone neutral. I want to protect my family."

PABC, Middlesbrough

"I'd prefer not to involve my boys too much in it – they'd worry 'why's Mum going on this? Is she short of money?' At the centre it would be more private."

PABC, Kings College Hospital

"A website has anonymity which is nice."

PABC, Macclesfield

- 2.6. One group of PABC who regularly attended a lung cancer group saw the tool being in the centre as **a social opportunity**.

"We could have a coffee and a chat and meet up – even though I have a computer at home. And we could discuss it. You'd meet new people."

PABC, Kings College Hospital

- 2.7. In terms of support, PABC were happy with the idea that this might come from **volunteers rather than centre staff**. PABC could commonly imagine wanting **support 'getting set up'** on the computers, such as logging on and being shown how to find BMC on the Macmillan site. For less IT-literate people the need for this initial set up support was extended to 'hand holding' through to the end of the tool, e.g. *"(support) to understand the wording"* (PABC, Middlesbrough). PABC also liked the idea that staff and volunteers could be on hand to help, particularly as a PABC in Derby envisaged support being useful when using the tool because, *"guaranteed I'd get stuck"*.

- 2.8. However, some also mentioned the possibility of needing **emotional support** *"just in case you burst into tears"* (PABC, Kings College Hospital) when faced with difficult questions about their condition. Some others thought more **specialised advice about how to use the tool** would be useful, and for example cited the way in which many had been prompted by Benefits Advisors to think about benefits from the perspective of a 'bad day' as valuable advice.

"It's actually difficult to realise, admit and be honest with yourself – you want to be treated as normal. (Therefore) I might not answer questions truthfully as I want to be better than I am."

PABC, Middlesbrough

- 2.9. Some thought there might be value in having easy access to the Macmillan Benefits Helpline from the BMC terminal so that any questions could be promptly followed up.

"If it flags up questions then you can ring someone, you won't do it when you get home."

PABC, Macclesfield

- 2.10. Patients liked the idea of **combining use of the tool with a hospital visit** and many could imagine 'having a play' with it whilst waiting for an appointment. The possibility of dropping in to use the tool was popular, and some were willing for this to be limited to certain days when resources and support could be made available. Overall, PABC were less likely to want to make an appointment to use the tool, and some felt this was a barrier.
- 2.11. PABC responses to when the tool would be most usefully used favoured a point **early after diagnosis and before treatment** has started, although it was acknowledged that this is sometimes only a couple of weeks. This was thought to be when the information would be most useful, as for some people money is a worry early on. It was also recognised that your condition may prevent you from accessing this information later in the cancer journey.

"I couldn't be bothered being on the computer during treatment."

PABC, Macclesfield

"It needs to be early on, before you lose your head."

PABC, Macclesfield

"After diagnosis but before treatment as treatment affects your thinking."

PABC, Derby

- 2.12. However, all PABC groups discussed the fine balance at this stage between being given useful information and being able to take that information in. It was therefore also important that the **information continued to be available** to PABC, not only to catch people who may not have absorbed the information when it was first given to them, but also to allow people to undertake second self-assessments if their condition or circumstances changed, or if they wanted to apply for different benefits.

"Once I got the hang of it I imagine I would need to go through it again (when changes occur)."

PABC, Middlesbrough

- 2.13. During the discussion with PABC, it became clear that many had been **hesitant or had encountered barriers to receiving benefits** and benefits advice. Some felt a stigma involved with benefits and financial advice, or had a perception that benefits weren't for them.
- 2.14. One PABC in Middlesbrough had worked all of her life before becoming ill with cancer and so was reluctant to claim benefits because of her work ethic and the stigma it held. She took the view that *"a lot of people are worse off, I'm not interested. When I'm feeling well I forget about my illness"*.

- 2.15. Other cited the very practical examples of being put off by long forms, feeling that the benefits system was too complicated, it was described by PABC as 'a muddy, foggy area' and 'a whole new ball game'. Many felt that the **tool had a role in highlighting that help was available** to those who might never have thought about benefits.

"I just accepted that I had what I had."

PABC, Macclesfield

"It might be a bit of help, and you might follow it up. It wouldn't cross your mind otherwise."

PABC, Macclesfield

"I've never claimed for anything before so something like this would help."

PABC, Derby

Cancer Nurses and other specialists

- 2.16. Only a small number of the Cancer Nurses and other specialists had had a chance to use the tool prior to interviewing.
- 2.17. Like PABC, Cancer Nurse Specialists and other patient-facing specialists saw BMC as **another tool available to them and to PABC** that could help satisfy the varied wants and needs of PABC. They thought that locating the tool in the centre meant that additional support would be available to them.

"Any links, or any support for these patients is useful."

Gynaecology CNS, Macclesfield

"I suppose if it's available online, a lot of people might do it if they have a computer at home. But at least if it's here then people can help them if they get stuck."

Bowel Cancer CNS, Macclesfield

"We give a lot of info out at different points in the journey. Some people read it all, some people put it in a drawer. Some don't want to know. We're all different."

Breast Cancer CNS, Macclesfield

- 2.18. One felt that the tool would allow staff to be more informative and thus **patients would have confidence in staff knowledge** of the wider implications of cancer.

"Signposting doesn't feel enough, but giving them extra info would be useful, for own use and to know what to advise people."

HPB Specialist, Derby

- 2.19. The views of specialists corroborated those of the PABC who knew of groups that would find the **anonymity** of this tool appealing, and that for these groups in particular BMC might be more appropriate than the Benefits Helpline.

"It's a bind ringing up somewhere you don't know, when you're not feeling well and we have patients who don't want to do that. One lady said she's worried about having to meet people - that's her stress. So talking to somebody strange and divulging personal information... The internet feels more anonymous really. It has that benefit."

CNS Gynaecology, Macclesfield

- 2.20. All were **willing to refer their patients to the tool** if it were available in their centre, but some said they would need to manage expectations by making clear that the tool would still give an onward referral. This said, specialists saw a number of benefits to the tool being available in the centre.
- 2.21. They thought it could **usefully target older people** who are less likely to access the tool online by themselves because they could get support and help in the centre. However, there was a question about whether older people may prefer not to use computers, and might find calling the Benefits Helpline, or getting face to face benefits advice more appropriate.
- 2.22. Some saw the tool's availability at the centre as a way **to reduce stigma** and encourage conversations about benefits and finance. This echoes the view of PABC who cited this as a barrier to getting benefits advice. Interestingly, this was flagged up as particularly relevant again to older people.

It's difficult for older generations who are a bit embarrassed talking about money. [Interviewer: So might it help older people having it in a centre?] Yes, but I think you would need a volunteer as well.

Palliative Care Social Worker, Kings College Hospital

- 2.23. A further strong finding was that specialists welcomed anything that might **get people into the centre** and then prompt other conversations or access to further services. This may also be a way of getting people who might be reluctant to seek support to set foot in the centre.

"It would get people into the centre, I can tell people they can come here and someone will show you how to use it. They might avoid coming here for whatever reason. Also if they're in here they can enquire about other benefits, other leaflets."

Bowel cancer CNS, Macclesfield

- 2.24. Again like PABC, most Specialists felt that **at diagnosis** was the right time for the tool to be introduced to patients. Partly this was in response to

demand for advice at this stage, but also reflected on the timescales sometimes involved in making a benefits claim which meant that starting early should help PABC avoid 'missing the boat'.

Volunteers

- 2.25. Most of the Volunteers whom we interviewed had seen the tool prior to interviewing.
- 2.26. Across the four sites where our research involved volunteers, volunteers themselves reported different motivations for becoming involved with Macmillan. They also showed **themselves to have a range of skills and levels of confidence**. A lot of volunteers did 'meet and greet' where they provide a listening ear to PABC in the centre, made them comfortable and directed PABC towards advice. However two sites gave their volunteers more specialised roles. These included one volunteer who was responsible for monitoring IT equipment and assisting in its use, and another group of volunteers who were trained to assist with access to benefits services.
- 2.27. Centre Managers reflected on volunteers as tending to be **computer literate**, with some exceptions. Centre Managers felt there were some limitations to the roles that volunteers could take on without training, and stressed **volunteers themselves would need to feel confident** with how the tool worked and how best to guide PABC through it, if they were asked to support users of the tool.
- 2.28. Volunteers themselves were **broadly supportive of the tool**, and many could see it adding value to the centre's information offer. Volunteers, like other groups, felt that the system would be another tool which they could offer to PABC, and this was felt to strengthen their role. They showed **a willingness to be trained** on how to use it, with the view that they could support users through it.
- 2.29. In one site where volunteers were already trained to guide PABC through their own paper-based benefits 'triage' tool, they had initially resisted the tool in favour of their own. However through discussion of how the tool might work, in particular if a laptop were available, they began to view it favourably and more so than the Centre staff.

Centre Managers

- 2.30. Almost all of centre managers and other centre staff interviewed had used the tool prior to our interviews.
- 2.31. A small number of Centre Managers felt that having the tool available in the centre would **enhance their overall benefit offer** due to them not having ready access to Benefit Advisors.

"Potentially it would help our role (staff and volunteers), as we wouldn't have to signpost as many people and it wouldn't delay getting information back (to people)."

Centre Manager, North Manchester

"It would boost it, (it would be) a very useful addition"

Centre Manager, Cambridge

2.32. Centre Managers were not particularly concerned about the tool having **impact on their workload**, but were aware that it would limit what they and their volunteers were able to do if PABC required monitoring whilst using the tool. In sites with only one member of paid staff, this monitoring could mean that they wouldn't be available for other PABC, especially if the tool was being used in a private or discreet area.

2.33. A more pressing concern was the potential increase in **questions about the benefits system** that they would feel unable to help with.

"I don't feel like we can advise sufficiently on benefits, if patients had a question it generates a much deeper discussion – both emotional and benefits related. Would we be sufficiently trained?"

Centre Manager, Macclesfield

2.34. However, there was also uncertainty about how the tool added value and most Centre Managers **expressed a strong preference for other benefits advice services** where available. This included the Macmillan Benefits Helpline which many had had good experience of, face-to-face consultation and, in one centre, its own paper-based benefits 'triage' tool.

2.35. Centre Managers felt some uncertainty around BMC in terms of whether it would really meet the needs of the PABC who used their centre. Their concerns were about the **overall outcome** of using the tool and that it does not give a definitive answer, **the amount of time it takes** and the **preference of some PABC for the human touch** when seeking this sort of advice. All Centre Managers expressed at least one of these concerns, but tended to see them as linked. For example, they may not mind that the tool is electronic, but might feel that spending thirty minutes on something that does not give a definite answer is not what PABC are seeking.

"I can see how it can have some use... immediate response, but my gut feeling is that people would prefer face to face service". For some people it's a good alternative."

Centre Manager, Portsmouth

"My preference would be to refer to a real person, then to the helpline, then Benefits Made Clear, with lots of caveats."

Mainly as Benefits Made Clear doesn't give an answer – which is what people come in for.”

Centre Manager, Kings College Hospital

“Historically PABC are very happy to have face-to-face support... the tool needs a personal touch, it's really good but you can't add in 'I wish I could just ask this question right now.”

Centre Manager, Macclesfield

- 2.36. In its current state, **many Centre Managers were not willing to refer PABC to the tool** because of the reservations outlined above. Despite these reservations, some Centre Managers were willing to promote the tool if Macmillan wanted them to do so.

Benefits Advisors

- 2.37. All of the Benefits Advisors interviewed had had a chance to use the tool themselves.
- 2.38. None of the Benefits Advisors had to date **seen any BMC print-outs from clients nor had felt an impact of the tool becoming available**. When asked whether the print-outs would be useful, responses were mixed. Whilst some said any information is useful, others felt that they would have to go over that information with the client regardless. None talked about it bringing a significant reduction to their workload, mainly because they saw the tool being used pre, rather than instead of, a Benefit Advisor appointment.

“As an advisor I am liable for my mistakes, so I would go through it with them anyway as I would be responsible for that.”

CAB Benefits Advisor, Kings College Hospital

“It would be useful to see the printout. Even if there is missed detail, I would then cover all the areas again...to confirm details.”

Benefits Advisor, Wythenshawe

- 2.39. Overall, Benefits Advisors felt the tool had a number of **limitations**, similar to those identified by Centre Managers. However, where Centre Managers were mostly concerned about PABC satisfaction with the service, Benefits Advisors were concerned that the tool could be used inaccurately and that people might mistakenly rule themselves out of qualifying for benefits.

"There is a danger of them doing something like self-diagnosis – I'm worried you would lose people (because of ruling themselves out). I see referral to an online tool as a negative due to the complexity of the system."

Home Visiting Benefits Service Co-ordinator, Suffolk

"Where benefits are concerned, it is very complicated i.e. do they (PABC) understand what the questions mean?"

Benefits Advisor, Wythenshawe

- 2.40. One Advisor feared PABC *"getting the wrong answer"* (Benefits Advisor, Derby) and felt that a face-to-face meeting with an Advisor may be able to identify any discrepancies which the tool may miss.
- 2.41. Some also felt it duplicated existing tools (such as direct.gov) and felt again that the helpline was preferable to using the tool.
- 2.42. There was a small number of Benefits Advisors who recognised that the tool **would provide 'a choice' to PABC**, giving initial insight to the complex benefit system and also ensuring anonymity, recognising this is some people's preference.
- 2.43. However, it should be noted that in one site which had a full time Benefits Advisor, the advisor was more positive about the tool than other interviewees had been. On that site, the staff had already developed a paper-based 'triage' tool which was used in conjunction with the Benefits Advisor's face-to-face service. This advisor spoke of how BMC could have a similar role in **complementing the benefits service**, as their triage tool currently did, and that it did have some advantages over it.

"Prompts for the BMC are better (than existing triage tool which) doesn't ask about carers." (The online tool would be) complementary to overall offer at the centre."

Benefits Advisor, Middlesbrough

Practical Implications

- 2.44. Our research identified a number of practical challenges to be overcome if the potential benefits are to be fully realised.

Context

- 2.45. Within the centres visited, there were examples of centres with varying levels of resource. In practice this meant different sized budgets, different numbers of paid staff and volunteers and different IT equipment in place. The centres also spoke of the different demands for benefits advice, which varied both from centre to centre but also within centres, for example by cancer type and cohort.

- 2.46. It is also worth noting as context that across all the sites, use of IT facilities by members of the public was low.

Privacy & confidentiality

- 2.47. On the whole, PABC were **happy with the levels of privacy available** to them in their centres and could imagine using the tool in the existing facilities. However, they could imagine some PABC wanting more privacy. In line with this, many thought that **flexibility on where the tool was available within the centre** would be important. For example, by having BMC available on a laptop which could be taken into a private room or a quiet corner, or having BMC available in more than one type of space. This message was particularly strong in a centre which adjoined with an Oncology Clinic waiting room, and so was seen as more bustling and less private than a standalone centre.

- 2.48. Observation of the sites showed a number of **types of private spaces** that could be used (some examples are illustrated here). These included bookable quiet rooms, computer rooms (which may have more than one terminal) and partitioned areas within the public main area.

- 2.49. The **audio element of the tool also has implications for privacy**. Many PABC were receptive to the idea of using headphones and this would allow more flexibility in where the tool could be located or used. However as discussed in the next section, the use of headphones in many NHS Trusts has hygiene implications.

- 2.50. **Satisfying a PABC's need for privacy may have implications for how staff resources are managed**. For example if a member of staff is required to guide a PABC on a BMC terminal in a private room then this will affect how the public spaces in the centre can be manned. One Centre Manager did suggest that it could be a balance between providing privacy as well as optimising access to the tool, and that if some PABC were not as concerned about privacy there were other parts of the Hospital, such as Macmillan Information points, where it could be made available.



NHS Policies – IT and hygiene

- 2.51. Two NHS Trust policies have implications for the piloting of BMC into health care Information and Support Centres. These relate to 'guided use' of IT facilities and hygiene.
- 2.52. One site had already experienced difficulties with **using shared media equipment that contravened Trust policy around hygiene**. This was especially pertinent in that centre, which is in close proximity to clinical wards. If headphones were to be offered at this site, the centre would need to purchase disposable headphones, which would require a budget.
- 2.53. Trust-wide '**guided use' policies required a member of staff or a volunteer to monitor any member of the public using the internet**. These existed at seven of the ten sites. This presents both a further challenge to resources, and potentially, difficulties in assuring appropriate levels of privacy and confidentiality to PABC who wish to use the tool discreetly. The low computer usage at sites has meant that no centre has felt the need to negotiate around this policy or push against it.
- 2.54. On one site there was open access to the internet, with no guided use policy because computer facilities were on the University's rather than the NHS Trust network. Although this would allow staff to let PABC use the tool independently, this set up meant that printing was only possible via the Centre Manager's NHS networked computer, which again limits potential for PABC to use the tool discreetly.

Training

- 2.55. It was felt that anyone giving support to PABC using the tool should be able to
- 'Set up' PABC on a terminal with BMC.
 - Understand the tool and be able to use it with ease
 - Be able to advise PABC on how they should answer questions
 - Offer emotional support if required
 - Understand and be able to explain terminology – eg. 'Carer'
- 2.56. 'Training the trainer' was seen as the most appropriate way of bringing skills and knowledge into the centres. **Centre Managers did not feel that much training would be required for them to be able to use the tool competently** and to be able to pass on their knowledge and skills to volunteers. Instead they felt that familiarity with the tool would suffice and some Centre Managers and volunteers talked about potentially role playing scenarios to aid learning.

Volunteers

- 2.57. Discussion with information experts within Macmillan identified volunteers as having a key role in determining how the tool would be used in Information

and Support Centres. Their ability and availability to assist PABC in accessing the tool, and their willingness to up-skill or learn about the tool, were seen to have important implications for how the tool will be used in centres.

- 2.58. From the perspective of Centre Managers, volunteers had varying abilities and specialisms, and **did not feel that all would be willing or capable of being involved with the tool**. In terms of knowledge and skills, with some exceptions, most were seen as being computer literate but without specific benefits knowledge. However, it should be noted that volunteers saw any information tool as a way of enhancing what the centre could offer, and therefore **they themselves expressed openness to the tool and being trained to use it**. The user-friendly nature of the tool was recognised by staff, Benefits Advisors and volunteers and so **gaining familiarity and confidence** with the tool was seen as the main requirement for volunteers to assist PABC to use to the tool.
- 2.59. At one site all volunteers had received training to help undertake the paper-based benefits triage tool with all PABC who came to the centre with benefits enquiries. This shows that amongst volunteers there may well be both willingness and capacity for involvement. If a more specialist role for volunteers was opted for, it is likely that **basic benefits knowledge would be the key focus of any training or up-skilling** and this would focus on understanding the criteria and questions within BMC.
- 2.60. In some centres where there were fewer volunteers, **volunteer help came in 'ebbs and flows'** and so was not necessarily a constant nor reliable resource.

Promotion

- 2.61. Overall, **types of print media were commonly suggested for promotion of the tool**. Examples were given including leaflets and business cards that could be handed directly to the PABC by a health professional with an opportunity for an oral explanation. Other methods of promotion suggested were visually strong advertising such as posters or an eye-catching BMC 'kiosk'. This was thought to be particularly important in encouraging PABC to 'drop in' and use the tool.
- 2.62. **Case studies or testimonials** were mentioned by some PABC as persuasive and they talked of the effect of "*a real face that would provoke you into finding out more*" (PABC, Macclesfield). It was also suggested that a **Macmillan 'Good Day' campaign** poster focusing on benefits advice issues might be effective.
- 2.63. Outside of print and visual media, one group of PABC suggested that **promoting the availability of the tool in a specific centre to cancer networks and patients groups** would be an effective way of getting the message out by word of mouth to users of that centre.

Referrals

- 2.64. Professionals such as Cancer Nurse Specialists (CNS), social workers and Centre Managers have a role in increasing access to the tool by referring PABC to using it in Information and Support Centres. Additionally, PABC at one site felt strongly that the CNS had a role in promoting this tool.

"You get a package at the beginning from your nurse ... information could be in there."

PABC, Wythenshawe

- 2.65. One CNS described herself as an 'information gateway' for patients and so their **ability and readiness to refer PABC to this tool** is helpful. CNS tended to say it would be easiest for them to refer PABC to the tool with printed materials like leaflets or a card that could be attached to existing information. They felt there would be some degree of managing the expectations of PABC to ensure that the purpose of the tool was made clear.
- 2.66. There was a consensus that the tool could be introduced to PABC shortly after diagnosis, which is when a large amount of information is given out to patients. Not only would this **flag up the opportunity to use the tool early on**, but would also get PABC introduced to the Information and Support Centres which was perceived as beneficial.
- 2.67. Centre Managers were less likely to refer PABC to the tool in its current form. Some managers were simply unclear on what the tool was intended for and did not really understand the value it added. This made them reluctant to refer PABC to the tool. **Centre Managers would welcome clarity from Macmillan on the tool's purpose and value added.** This would allow them to refer, knowing it would genuinely help PABC as well as being able to communicate this effectively to volunteers who might feel similarly unsure.

"What can a volunteer say to a PABC who asks 'why did we just do that?' ... It would be helpful to know what BMC tool developers think they can get out of it."

Centre Manager, Kings College Hospital

3. PRELIMINARY CONCLUSIONS AND RECOMMENDATIONS

- 3.1. The research suggests that the original conception and the design of the tool itself was a valuable response to important issues facing PABC with financial concerns. The availability of the tool was welcomed resonating particularly strongly amongst PABC. There were though important cultural differences in the perceptions of the tool's ability to make a significant contribution to addressing those concerns (particularly from Benefits Advisors) and some significant practical challenges to be addressed
- 3.2. Based on the evidence outlined in this document, the following recommendations are made:

General

- 3.3. PABC have **varied needs and wants regarding information**. It should be recognised that making this tool available within health care settings such as Information and Support Centres will work for some, but not for others.
- 3.4. Any piloting of this tool needs to be nuanced and to take account of the differences between Information and Support Centres. In working with centres on piloting and any subsequent roll-out, the project team should be flexible and **allow space for local centres to influence decisions on implementation**.

Training

- 3.5. Any training offered alongside the introduction of the tool should be aimed at Centre Managers, who will **cascade knowledge and skills down to volunteers**.
- 3.6. Training needs to stress **the stand-alone nature of the tool** and assure Centre Managers that PABC could use it without intensive staff support.
- 3.7. This **training should be light-touch**, and aim to give Centre Managers a working knowledge of the tool and how PABC can get the most value out of using it.
- 3.8. An additional training and support need may be to encourage or advise Centre Managers on how **to negotiate around trust-wide policies** such as 'guided use' internet policies.

IT

- 3.9. Centre staff were concerned by the pressures on their own and volunteers' time caused by the 'guided use' requirements of some Trusts. As Trust-wide

IT policies have been largely unchallenged by centres, Macmillan should be **prepared to support and encourage staff in local negotiations**, where centres are experiencing difficulties.

- 3.10. Where avoiding such policies is not possible, **CD ROMs** containing the tool may be a suitable solution.
- 3.11. However given the current scepticism of some Centre Managers and their unwillingness to refer PABC to the tool, the pilot phase of implementation in health care settings should be used to **investigate the business case for investing in CD ROMs**.

Volunteers

- 3.12. Where volunteers may be required by a guided use policy to accompany a PABC using BMC, it would be worthwhile for **volunteers also to be trained to be able to offer support to PABC**.
- 3.13. As outlined in the evidence, **support does not entail giving expert benefits advice**, but volunteers would need to be confident enough to deal with PABC questions. For example, seeking clarification about the terms and questions used in the tool and how to answer them realistically and appropriately. This requires an understanding of how the tool works and how PABC can get the most out of it.
- 3.14. Evidence also shows that volunteers should be prepared and able to give emotional support to users of the tool if required.

Promotion

- 3.15. Information about the availability of BMC in a health care setting should be added into **existing financial advice leaflets** and other information products, rather than producing new, lengthy literature.
- 3.16. A **business card** with details of where the tool is available is popular with PABC. This business card should show the whole suite of available benefits services firstly as this will present a number of options to PABC and improve choice.
- 3.17. **Utilise the contact that health professionals and cancer nurses have with PABC** as research has shown them as willing advocates of the tool. In particular, they are well placed to hand out business cards to patients who request benefits advice, or to act as a Trust 'Champion' for BMC. Additionally, in some areas it may be possible to link BMC into the holistic assessments model being used by Cancer Nurses.

Communications Campaign

- 3.18. It is clear from this research that Centre Managers and Benefits Advisors, two key roles within Information and Support Centres, remain uncertain about the value of the tool, and its accuracy.
- 3.19. To accompany the pilot and any subsequent roll-out there needs to be a **communication campaign to ensure Centre Managers and Benefits Advisors 'buy in'** to the BMC tool. Concerns were clearly and consistently articulated, and some key messages for these groups can be established.

Centre Managers

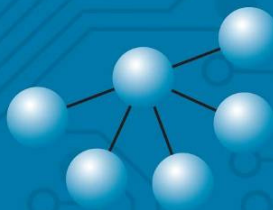
- 3.20. The key message for Centre Managers is that Macmillan is confident in the value of this tool and is clear how it is intended to add value to PABC. To do this, the campaign should
- Outline the rationale for the tool's development and Macmillan's vision for it adding value. In particular, make clear the potential to open up access to the tool to groups who may not be able to access it alone, and secondly that its availability at centres is one way to embed access to financial information into care pathways.
 - Clearly communicate the context the tool exists in. For example, state that it costs less than 1 Macmillan Benefits Advisor, it has already been used by 30,000 PABC compared to 15,000 who have called the helpline and that it is part of a suite of options to meet the wide range of needs that PABC have.
 - Use evidence from this report of PABC's positive view of the tool.
 - Explain how the tool has been improved (eg pace can be speeded up) in response to user feedback.
 - Use evidence from this report of the willingness of volunteers as a resource.
 - Use very short case studies of users it has benefited, or centres that have made it work (when available).
 - Emphasise potential for its use when waiting for a hospital visit.
 - Emphasise that it is standalone, and could be used without additional staff resources.
 - Include User FAQs such as: How will this tool help me?; Why does it go at a slow pace?; Why does it only cover certain benefits?; Why does it ask some things more than once?; Why can't it give me a definitive answer?; How can I find a Benefits Advisor?

Benefits Advisors

- 3.21. The key message for Benefits Advisors is that the tool is methodical and thorough in its process, which is designed to give an accurate indication of

eligibility of PABC, with regard to the five benefits pathways covered. To do this, the campaign should:

- Outline the rationale for the tool's development and Macmillan's vision for it adding value. In particular, make clear the potential to open up access to the tool to groups who may not be able to access it alone, and secondly that its availability at centres is one way to embed access to financial information into care pathways.
- Clearly communicate the context the tool exists in. For example, state that it costs less than 1 Macmillan Benefits Advisor, it has already been used by 30,000 PABC compared to 15,000 who have called the helpline and that it is part of a suite of options to meet the wide range of needs that PABC have.
- Explain how the tool has been designed to avert people mistakenly ruling themselves out of the five benefits covered.
- Use evidence from the testing with a large sample of Benefits Advisors who were positive about the tool.
- Stress that although the tool is standalone, it is intended to *complement* a Benefits Advice service.
- Stress that the tool is a source of information for them when PABC come to their service and may ease some elements of their workload, such as obtaining a PABC's NI number.



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