University Hospitals Bristol **NHS**

NHS Foundation Trust

IAM PORTAL PROJECT 2015-17

EVALUATION REPORT

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Contents

1 Introduction

This report presents the data produced through a series of evaluations as part of the 2015-17 IAM Portal project[1]. The aim of this report is to summarise the outcomes of the evaluations and append the detailed results for the purposes of reporting to the IAM Portal steering group. It is designed to act as a repository to draw on for future reporting or information as required.

The IAM Portal is made up of three components which are designed to work together to provide a developmentally attuned digital platform to enable professionals and young people to work in partnership through the young person's cancer journey, living with and beyond cancer. It utilises and builds on the outputs of the Macmillan On Target Programme which ran from 2011 -15[2] and aims to support the young person to be an active participant in their care and facilitate supported self-management when treatment has finished.

The three components of the IAM Portal are:

1. A TYA holistic needs assessment: The Integrated Assessment Map (IAM)[3]

The IAM is an age specific, multi-domain framework which provides a structure to support professionals and young people in holistically assessing needs for information and support at any point in their cancer journey. It is designed to look at the impact of, and adjustment to, their cancer and its treatment within a bio-psycho-social-educational-vocational framework i.e. what does having this cancer and its treatment mean for this young person and their support network at this point in time. The IAM has been developed for access via a website (www.tyaiam.co.uk) and an app, available on Android and Apple mobile devices.

2. TYA information and advice resources

Each domain of the map links directly to multimedia resources to support professionals and young people in assessing their needs and engaging in supported self-management from diagnosis through to living beyond cancer. This component was originally co-designed with professionals and young people as part of the On

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[1] IAM Portal Closedown Report. (2017). http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bhoc/teenage-and-young-adult-cancer-service/service-development/ Accessed 24/07/201
[2] On Target Closedown Report. (2015). http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bhoc/teenage-and-young-adult-cancer-service/service-development/ Accessed 24/07/2017
[3] On Target Intervention Report: IAM Project. (2015). http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bhoc/teenage-and-young-adult-cancer-service/service-development/ Accessed 10/07/2017

Target programme and is also directly accessible as the Help! website[4] (www.tyahelp.co.uk).

3. The TYA South West Integrated MDT Management System (SWIMMS)

This system provides the IAM portal with the framework to register young people into the TYA Service, submit an IAM to the team and MDT discussion, facilitate the discussion of an IAM structured young person's holistic needs, record outcomes of the MDT discussion and act as a repository for the resulting anonymised data on epidemiology and holistic needs of the population of teenagers and young adults with cancer covered by the regional service.

The aims of the 2015-17 IAM Portal project were to:

- Evaluate the co-design and implementation of an app version of the IAM holistic needs assessment access to the portal in the South West TYA Service
- Evaluate the implementation of SWIMMS as part of the portal in the South West
- Evaluate the implementation of the portal in another regional TYA service – the East Midlands pilot project

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[4]On Target Intervention Report: Help. (2015). http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bhoc/teenage-and-young-adult-cancer-service/service-development/
Accessed 10/07/2017

2 Methodology

An approach utilising mixed methodologies to enable the capture of qualitative and qualitative data appropriate to the aim of each of the evaluation areas was developed. This included web analytics, service data, MDT non-participant observation, surveys, interviews and focus groups. Relevant data from the On Target programme was also drawn upon to inform this process. The South West was also used to test evaluation methodologies for the East Midlands pilot project.

The South West TYA Service has been utilising digital versions of the IAM and Help! websites since November and May 2014 respectively and provided the test bed for the iterative development of the portal. The new developments requiring evaluation within the 2015-17 IAM Portal project were the introduction of the app and the SWIMMS system.

The aim of the pilot in the East Midlands was to test whether the IAM Portal could 'lift and shift' to another regional TYA cancer service. The evaluation plan (Appendix A) aimed to capture the experience of professionals and young people, the impact on the MDT and provide information on to inform future decisions on whether to roll out the Portal nationally through Teenage Cancer Trust and partners. This required evaluation of the preparation for implementation and early indicators relating to organisational impact and changes to roles (e.g. the MDT co-ordinator, TYA Specialist Nurses).

## 3   Evaluating the implementation of the IAM Portal app and SWIMMS in the South West

3.1   The IAM portal app

An initial evaluation using routine service data and Google analytics was undertaken from 30/8/16 – 31/10/16. During this period 15 young people were signposted, by the TYA team, to the app as an additional means of accessing the IAM Portal. Following the allocation of their log in, 12 (87%) of these young people had an IAM completed using the range of possible approaches: undertaken by young person independently, undertaken in partnership with a TYA professional or undertaken by a professional as a reflection of their assessment of the young person's needs.

The data available from Google analytics indicated 35 active users of the app during this evaluation period. This represents use by both TYA and professionals (as confirmed by later surveys and interviews). The following table summarises the data available:

| Users	35
Sessions	76
Returning users	59.2%
Screen views	589
Screens per session	7.75
Average session	3.20mins (range 0secs – 24mins)
Reported crashes	0

To support access to the app and the portal, TYA specialist nurses were issued with iPads. From the analytics available, a range of operating systems were utilised to access the app and on one occasion also using the opportunity to provide feedback:
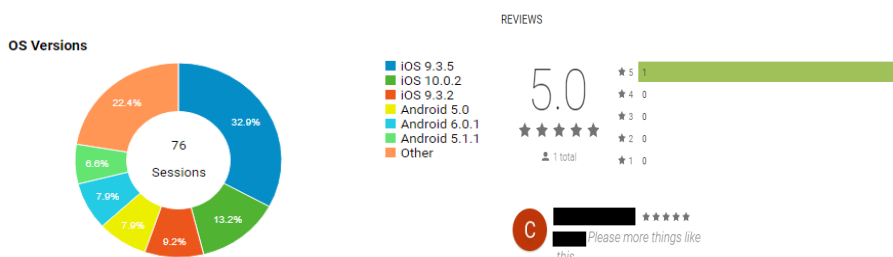
In January 2016, a further evaluation was undertaken to capture experiential feedback from professionals and young people who had accessed the IAM Portal via the new app. This was undertaken through the use of questionnaires and requests for telephone interview follow up. The questionnaires and responses can be found in appendices B – F. Nine professionals

and 46 young people were contacted. Responses were received from nine professionals (100%) and seven young people (15 %).

All respondents were asked to indicate if they would agree to be contacted for telephone interview by someone outside the immediate South West TYA team (the East Midlands pilot project Portal Co-ordinator). Three young people agreed to be contacted but did not respond to contact. Eight out of the nine professionals participated in the semi-structured interview and their comments are summarised in Appendix G.
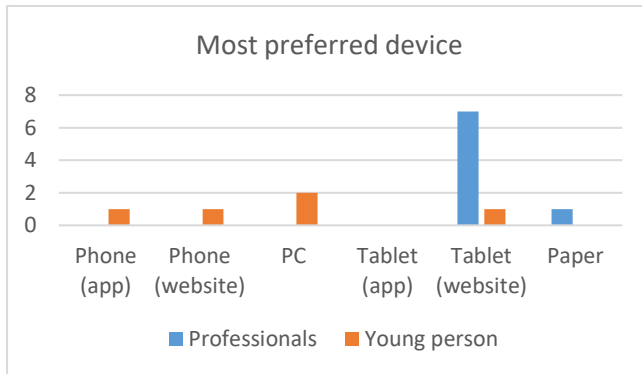
The development of the app was initiated by, and co-designed with, young adult service users to complete the 'menu of options' to access the IAM Portal across devices, consistent with the findings from the On Target requirements analysis work[5].
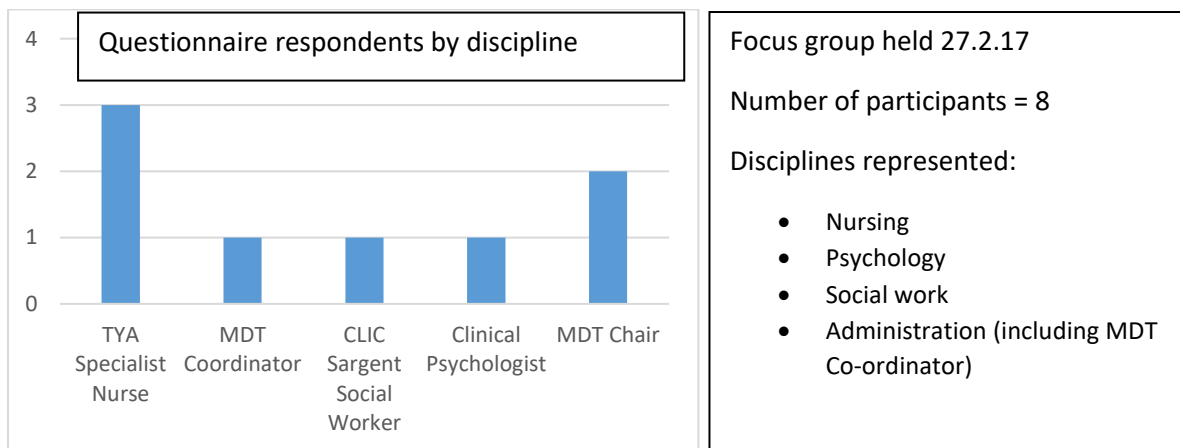
Initial evaluation of the app has not flagged any significant issues with user acceptability and wider implementation and evaluation is indicated.

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[5] On Target: Patients' workstream – findings report. (2013). http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bhoc/teenage-and-young-adult-cancer-service/service-development/ Accessed 24/07/2017

3.2   SWIMMS

Regular members of the weekly regional on line TYA multidisciplinary teams advisory meeting (the MDaT), which is the South West version of the TYA MDT, were invited to complete a questionnaire and contribute to a focus group discussion on their perception of the impact of adding SWIMMS to the IAM and Help! components to complete the three interconnected elements of the IAM Portal. A copy of the questionnaire and the responses to it and the focus group can be accessed in Appendix H and I. Qualitative feedback from the questionnaires and the focus groups were collated under three main headings:

- Comment on experience
- Suggestion for improvement to SWIMMS that could be translated to a change request for the system build
- Add to IAM Portal Guide for future

Questionnaire respondents by discipline

Focus group held 27.2.17

Number of participants = 8

Disciplines represented:

- Nursing
- Psychology
- Social work
- Administration (including MDT Co-ordinator)

In summary, the questionnaires show a positive response to the use of the SWIMMS to enable IAM based discussions to be held in the TYA MDT. The qualitative data from both the questionnaires and the focus group were used to inform change requests for the system and contents of the IAM Guide in readiness for the East Midlands implementation pilot.

The questionnaire was reviewed for utilisation in the East Midlands IAM Portal pilot, in particular for evaluating the Portal's impact on the MDT processes from registration to outcomes and the use of the IAM domains to support the holistic needs discussion.

4   Evaluation of the IAM Portal pilot implementation in the East Midlands TYA Service

This pilot was designed to test whether the IAM Portal could migrate to another TYA regional service and learn from this experience, particularly in relation to the preparation, engagement and information required from future Trusts and Cancer Services if this system were to be rolled out more widely. The pilot period ran from 17th January 2017 until the 19th May 2017, with a staggered introduction to the systems in to the service:

- Planning and information sharing with the East Midlands team: June – Dec 2016
- Implementation preparation with Lead Clinicians, Lead TYA Nurse, TYA Specialist Nurses, MDT co-ordinators and other TYA MDT members: Nov – Dec 2016
- Baseline MDT observation: 18th November 2016
- IAM Portal shared with young people: 17th January 2017
- SWIMMS introduced: 27th January 2017

The actual pilot period was shorter than originally planned due to delays in the completion of the SWIMMS build. This had a limiting impact on the number of young people who were able to experience using the Portal, the opportunities for professionals to experience using the portal, the number of MDT discussions to familiarise and develop the use of the IAM domains to enhance the holistic assessment process and the use of the submitted IAMs to address the holistic needs expressed by the young person. It also limited the amount of service related, analytics and qualitative data available. To somewhat mitigate this, the project steering group agreed to extend and repeat the questionnaires and MDT observations at a second time point.

This section of the report will present the data produced by the pilot. The questionnaires and semi structured interviews developed and tested in the South West, as outlined above, were migrated to the pilot project without amendment. The areas to be addressed will be:

- Can the IAM Portal be beneficially implemented in another TYA service?
- Could this be replicated in other areas and if so, what would be required to enable this to happen?
- What are the experiences of young people in utilising the Portal?
- What are the experiences of professionals in utilising the Portal?
- Does the use of the Portal impact on the function of the TYA MDT?

4.1   The experience of young people

Over the pilot period, 55 logons were allocated to young people accessing the East Midlands regional TYA service based in the two Primary Treatment Centres (PTCs) in Leicester (22 logons) and Nottingham (33 logons).
The following graph illustrates the number of assessment maps (IAMs) submitted over the pilot period and how they were completed. Integrated assessment mapping and accessing

resources on the Help! pages may be undertaken independently by a young person, in partnership with a professional as part of care planning or by a professional to share their perception of a young person's needs in the MDT. At diagnosis or other key points such as a significant change in prognosis or ending treatment there may be a planned IAM based review of needs in partnership with a professional however the Portal is designed to be used as flexibly as possible by both young people and professionals.

In this short pilot, it was positive to see evidence already of young people submitting an independent IAM and that some individuals submitted more than one IAM indicating a perceived change in need. One of the developmental areas for the MDT was the potential to use the IAM during the patient discussion to record the professional's perception of the young person's needs.
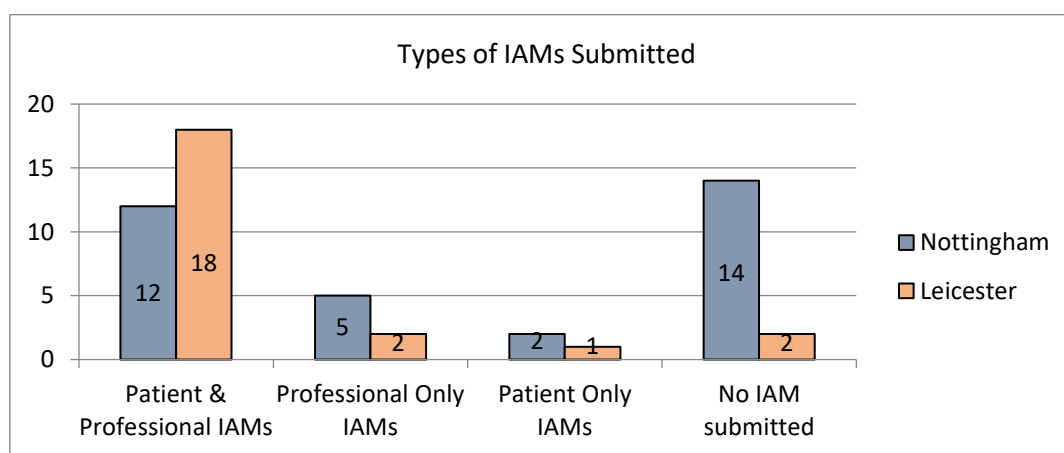
This data is consistent with the breakdown of submitted IAMs in the South West, in 2016 for example, 77% percent of young people with IAMs completed had contributed directly by either completing one independently, or in partnership with a healthcare professional (as opposed to the assessment being professionally led).

The available analytics for the pilot period are summarised below and available graphically in Appendix J. This data cannot illustrate an individual journey through the Portal (e.g. the interfacing between the needs assessment and accessing Help!, however this will be available in the future when the websites are combined).

	IAM app	IAM website	Help! website
Users	43	270	224
Sessions	114	733	335
% new to return users	24.6: 75.4	32.3: 67.7	61.5: 38.5
Screen or page views	1, 062	6,236	1,733
Screen or page / session	9.32	8.51	5.17

Data on the experience of young people was collected via a questionnaire sent from the IAM Portal Project Support Coordinator or the relevant TYA Clinical Nurse Specialist (CNS). Due to the time constraints, there was no reminder email and the in the original

distribution, young people were also asked if they would be happy to be contacted to discuss their experience in further detail. One young person agreed to this but as in the South West final contact to engage was not established.

Six (11%) young people provided with a logon completed the questionnaire, and the full responses can be found in Appendix K. All respondents had used the portal to complete an IAM and two had also accessed the resources in Help! Given the short pilot period and small number of respondents at this stage we can only report the data noting that although a small sample the questionnaire feedback is on the whole positive. Four of the young people (66%) stated they would recommend the IAM Portal to other people (the other two were unsure) and comments such as *"I liked it because I feel it's just for young people to give their thoughts and ideas. It gave me time to think, everyone should have a go because it's really useful",* were early indicators that the concept of supporting young people in expressing their needs could be replicated through use of the portal in another TYA regional service.

Young people were asked to rank their preferred device or method of accessing the portal and the app by phone or tablet and website by tablet were all voted for. This again reiterates the South West findings that young people want multi device and operating system choices.

4.2   The experience of professionals

Questionnaires were sent to the regular attendees of the East Midlands TYA MDT at two time points. The first questionnaire opened on the 2nd March 2017, and the second at the end of the pilot period on the 10th May. The first questionnaire referred to as the 'review questionnaire' was split in to three sections and targeted for respondents who used the Portal for these purposes:

a) using the IAM with young people (N= 4)
b) SWIMMS and the MDT (N=15)
c) preparation for the pilot (Appendix L) (N= 15)

The final questionnaire issued at the end of the pilot period only contained two sections:

a) using the IAM with young people (N= 3)
b) SWIMMS and the MDT (N= 9)

The full data set at both questionnaire points and the respondent's profile is included in Appendix M. The responses indicate that professionals can see the positive potential for the use of the Portal both in direct working with young people and to support holistic discussion within the MDT however they feel they would like more time to experience its use and become more familiar with integrating its use into their day to day working.

The changes to the registration, administration and discussion of young people at the MDT as a result of using the SWIMMS component of the portal were focused on as part of the questionnaire. The full data is presented in Appendix N. In addition to the questionnaires, ten professionals agreed to a semi structured interview and this data is available in Appendix O.

The data illustrates movement towards a more positive evaluation at the final time point and combined with the qualitative feedback, confirms the need to allow sufficient time for staff to familiarise themselves with the system's technology requirements and also the process changes it influences (i.e. how a patient is discussed at the MDT and recording action based outcomes). The following quotes are representative of the themes running through this data:

"I have not personally used the IAM with young people, but have been involved in discussions using the IAM portal and data base at the MDT. I think the IAM focuses the discussion and has led to more psychosocial aspects of our patients being considered and addressed. The experience has generally been positive, although there were significant teething problems"

"I think that it varies greatly from each young person, but it is down to us as professionals to work out how we use it. It will benefit those who engage with it, still a lot of learning to be done but I think it will be great"

"I think the IAM portal system as a whole is a great concept and will be of great benefit for both patients and clinical teams. I think we need longer in order to gain a more informed picture of how the patients and TYA team feel about its worth. The data outcomes we will be able to pull from the SWIMMS system will be fantastic and powerful particularly as it will be consistent across the UK"

4.3 MDT observations

Appendix P contains the data recorded by non-participant observers using a bespoke coding system to capture which professionals are communicating and what they are communicating (information, question, action point) relative to each domain on the IAM holistic needs assessment and the clinical fields on the SWIMMS registration and outcome pages. The reliability and consistency of the coding categories between observers was assessed through a South West TYA MDT using the two observers who proceeded to use the approach to gather data from East Midlands TYA MDTs. Three time points were used: baseline (18/11/16), review (03/03/17 after six MDTs) and end of pilot (19/5/17 after sixteen MDTs).

The data recorded at these MDTs has been triangulated with the questionnaire and interview data. It confirms that the use of the portal is supportive of holistic discussions within the MDT and can enable all members of the multi-disciplinary to contribute to the discussion. The East Midlands MDTs were already having holistic discussions at baseline. Professionals have commented on its potential to increase the psycho-social content of the discussion and the observational data confirms this.

The portal is designed to support the functionality, out puts and outcomes of an MDT from systematically adopting a young person's perspective through to the valuing of multi-disciplinary team member's contributions and the collation of population data that will influence future service provision based on young people's expression of their holistic needs. The pilot project MDT observation and experiential feedback evidences that the system can be supportive, however, the quality of this will be dependent upon the way in which it is used by professionals and young people from individual assessment experiences

to the content of MDT discussions. This again confirms the need for time for individual services to consider how to make the portal work for them once they have gained familiarity with all its components.

4.4   Pre-implementation preparation requirements

As this was the first experience of implementing the portal in another regional service data was also collected on the preparation activity and resources. A summary of the preparation grid can be found in Appendix Q. Data was collected through questionnaires and reflective feedback from participants. This is detailed in Appendix R.

To summarise the feedback, future preparation for implementing the portal should include:

- Early engagement with clinical, nursing and management leadership from both the TYA service and the wider organisation e.g. the Trust's cancer board to co-produce the local implementation plan, identify resource implications and enable these to be utilised
- Training on using the portal with young people, within the MDT and as a service support tool should include:

  - multi –media information for young people as well as professionals
  - observation of its use in a service where it is already 'business as usual'
  - opportunities to have supported experimental sessions and simulated or dummy runs from a partnership IAM through to its MDT discussion
  - ongoing support during the initial implementation period with an early review to assess impact and experience as part of an iterative transformation plan.

This evaluation data will be taken forward to form the basis of future pre-implementation planning and checklists.

5 Conclusions and recommendations

This report provides qualitative and qualitative data relating to the implementation of the IAM portal app and the addition of SWIMMS to the portal in the South West plus the pilot implementation of the full portal system in the East Midlands TYA service as delivered by the 2015-17 IAM Portal project. The key conclusions and recommendations for next steps are summarised below:

5.1   Key conclusions

5.1.1 The IAM Portal app is now fit for purpose and completes the multi-device and operating system offer for young people and professionals to use when accessing the assessment and resources components of the portal.

5.1.2 The SWIMMS is now sufficiently functional to support registration, IAM submissions, MDT organisation and care planning outcomes. The extraction of whole population data is possible but has yet to be tested outside the South West due to data availability.

5.1.3 The IAM Portal can be beneficially implemented outside the South West TYA service with sufficient preparation and support. Detailed information on who to engage with, what to cover in the preparation phase and how this can be undertaken can be developed based on the extensive qualitative and quantitative data available from the pilot project. The time to embed the portal into all aspects of the service needs to be recognised with a realistic review point before using any post implementation evaluation measures.

5.1.4 The successful use of co-design for both the portal and its implementation should be continued.

5.1.5 Experience to date suggests that the evaluation methods employed during this project are fit for purpose and could provide a cumulative core data set for each new future implementation and evaluation. Potential data set summarised below:

Quantitative metrics	
Impact and value for TYA	% new patients have IAM based MDT discussion at diagnosis
	% patients have IAM based MDT discussion prior to moving off treatment
	IAM based discussion outcome measure completed by TYA at diagnosis (portal usefulness / helpfulness)
	IAM based discussion outcome measure completed by TYA at off treatment (portal usefulness / helpfulness)
	TYA outcome report post IAM led MDT discussion (submission to MDT, discussion and actions usefulness / helpfulness)
Device activity and content feedback	Google analytics
	Page * ratings and comments
Impact and value for staff	MDT observation and reflection self-assessment

	Annual experience and improvement survey
Epidemiological	Population needs data by domain / condition/ etc
Mixed methods	
Impact and value for TYA	Annual NHS TYA survey specific value based questions re IAM Portal use (map and Help!)
	System content co-design outputs

5.1.6 Following a review of their pilot experience the East Midlands team and their Cancer Board have agreed to continue with the use of the Portal which would enable further valuable evaluation of its impact and value as familiarity increases and the population of young people engaging with it increases.

5.2   Recommendations

5.2.1 The learning from the preparation for implementation evaluation should be developed into a 'IAM Portal readiness' to guide future implementers, with particular regard to:

- Local engagement and leadership for the implementation
- Early discussion with information governance and information technology teams in the NHS Trust to ensure the digital platform can and will be supported on Trust equipment and all Trust information governance requirements are met
- Early awareness and support from the local Cancer Board
- Early awareness and support from the Macmillan E-HNA team
- Resource available for key role in MDT co-ordination
- Time available in job plans and roles for initial transformation work

5.2.2 An electronic information pack for prospective sites should be developed from the legacy documentation, to include:

- Overview of the IAM Portal, outlining each component
- SWIMMS and MDT chairing guidelines
- Data extraction from SWIMMS examples and guidance
- Macmillan letter (Appendix S)
- Security letter (Appendix T)

5.2.3 The findings from the evaluation in the South West and East Midlands have contributed to the system enhancement work, scheduled for July 2017 (change request in Appendix U). This work will be completed before the system is implemented elsewhere.

5.2.4 To date there has not been a research programme aligned to the impact, value and cost benefit analysis of the portal. There are a number of timely research projects relating to digitalisation, empowering young people in transition, supported self-management and living beyond cancer for TYA that could be aligned to a future portal implementation programme.

5.2.5 The data set described above (5.1.5) requires review and alignment with the planned outcomes framework being developed by Teenage Cancer Trust.

5.2.6 Future development of the portal should adopt and reflect the strategic directions being taken by NHS digitalisation, national cancer bodies and local Trust alliances and cancer boards.

5.2.7 The relatively low response of young people to interview follow ups should be considered going forward. In previous On Target evaluations[567], engagement from young people has been higher. It would be worth considering the methods used in previous projects, and whether the expectation of supported engagement and feedback from host teams is more explicit. Continued evaluation through feedback mechanisms should also be considered to avoid overburdening the young person population.

5.2.8 The raw data produced by this evaluation as identified in the appendices throughout this summary report, are stored securely by University Hospitals Bristol NHS Foundation Trust. They are available for further analysis, replication and reproduction through the IAM Portal National Steering Group.

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[5] On Target: Patients' workstream – findings report. (2013). http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bhoc/teenage-and-young-adult-cancer-service/service-development/ Accessed 24/07/2017

[6] On Target Intervention Report: Help. (2015). http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bhoc/teenage-and-young-adult-cancer-service/service-development/ Accessed 10/07/2017

[7] On Target Intervention Report: IAM. (2015). http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bhoc/teenage-and-young-adult-cancer-service/service-development/ Accessed 10/07/2017