

INTERVENTION REPORT



IAM Website Development

ON TARGET: Enhancing the future for young people with cancer

ON TARGET is a service evaluation programme funded by Macmillan Cancer Support. Working with patients, the people who support them, professionals, charities and local organisations, the programme aims to assess and enhance the care offered to Teenagers and Young Adults (TYA) with cancer across the South West.

The ON TARGET team has gained a thorough understanding of the needs and wishes of TYA, those who support them and those who treat them. This knowledge has been used to design a programme of interventions intended to improve patient outcomes, increase self-management and reduce future healthcare demands. The selected interventions have been piloted and evaluated. Based on these findings, proposals will be presented to commissioners, the voluntary sector and health care providers to suggest changes to care that will most effectively ensure that “each TYA patient is supported towards re-engagement with life as it would have been without the intrusion of cancer or as the patient decides to recreate it after experiencing the impact of cancer”.

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1. Executive Summary

1.1 Background

Understanding the needs of Teenagers and Young Adults (TYA) is key to ensuring that they receive the care, support and information they require after their cancer diagnosis. This assessment of need must reflect what “having this cancer and its treatment means for this young person” and should be patient-driven, not based on professional assumption.

The Integrated Assessment Map (IAM) allows TYAs to assess and indicate their level of need (scale 0 - 3) in 10 domains which include areas such as Physical Wellbeing; Family Relationships; Education/Work; Emotional Wellbeing; and ‘My Condition Now’ (reflecting their perception of need around the impact of their diagnosis, treatment, prognosis etc.).

Phase 1 of this project introduced, trialed and reviewed the IAM concept during 2013 and the experience gained and the lessons learned, from this trial gave rise to the scope of the current Intervention which was mainly concerning the creation of the IAM website.

1.2 Methodology

A co-design approach was used with TYA patients and health care professionals (HCP) to re-develop the phase 1 IAM into a web-based platform providing a portal for use by TYA to assess: how the diagnosis has affected them, to identify and prioritise their needs, and to access support and information.

Functionality developed during this project included :

- prompts to help response / scoring
- links to information resources
- tracking of repeat assessments
- authorisation for access by / meetings with HCP
- summation of anonymised patient data to provide a needs profile for service evaluation

1.3 Results and Conclusion

In a 10 week initial pilot to evaluate functionality and relevance for service delivery, 29 out of 40 (72%) TYAs who were approached and allocated a logon, accessed the site, with 17 out of this 29 (59%) submitting at least one IAM to their relevant HCPs.

Feedback from the pilot has indicated that both TYAs and HCPs value this approach as a means of facilitating relevant and insightful conversations into patient needs and that the patients also value the fact that the IAM offers a private, secure, repeatable way for them to assess their changing needs; access information relevant to them; and to remotely transmit information about their concerns to their HCPs. In addition, the IAM also provides HCPs with a tool for reviewing, summing and responding to patient need and it provides the TYA service with data collection to guide service delivery and for the assessment of unmet need.

As a result of the pilot, the IAM has now become “business as usual” for the TYA Service team and it is proposed that further development of the IAM as an “app” for smart phones / tablets will ensure wider accessibility and will help retain the patient voice in service delivery.

2. Intervention Background

2.1 Basis of the Intervention

.1 Definitions

<i>IAM</i>	Integrated Assessment Map.
<i>HNA</i>	Holistic Needs Assessment
<i>MDaT</i>	Multi Disciplinary Advisory team
<i>Networker</i>	Throughout their cancer journey, patients will often gain support from a wide range of individuals who have relationships with them outside the healthcare setting e.g. family members, friends, work colleagues, professionals in educational institutions and others. As most young adults will also have significant relationships with individuals outside their family group, the term ‘family and carer’ is inappropriate for this network of supporters and as a result, the term “Patient’s Network” has been coined. A <i>networker</i> is an individual member of the <i>patient’s Network</i> .
<i>PROMs</i>	Patient Reported Outcome Measures
<i>PREMs</i>	Patient Reported Experience Measure
<i>PTC</i>	Principal Treatment Centre
<i>CMS</i>	Content Management System

.2 Project Background

NHS Cancer Peer Review standards require that all patients are offered a holistic assessment of their needs. In 2011, the TYA SW clinical service team decided to move on from the assessment tool being used at that time to utilise a more bio- psycho- social approach and one that also integrated more fully with medical factors. In addition, there was a need to design an assessment that used stratification of needs and incorporated outcome measures.

A review meeting, held to address the above points, generated the idea of a multi-domain model which could provide a structure to ensure that all young people were offered assessment and review discussions that incorporated the impact of cancer and its treatment within a bio-psycho-social-educational-vocational framework.

In addition, it was also recognised that there was a requirement to evaluate :

- whether the needs identified by the assessment and review process were met
- the value to the young person of the intervention / support from staff across the clinical network

Throughout 2012, further work on the framework was undertaken to develop an integrated model that could accommodate a range of assessment information that might be captured by members of the TYA or site specific teams around the young person (medical, nursing, social work, psychology, youth work), from the perspective of:

- a) asking and listening to what having *this* cancer and its treatment means for *this* young person and their support system

- b) sharing information from professionals on what to expect and what support is available
- c) negotiating, in partnership with the young person, what interventional support would be offered
- d) building an overall care plan, including the identification of a keyworker etc.

This work generated the Phase 1 Integrated Assessment Map (IAM), which was introduced, trialed and reviewed at the end of 2013 (details are contained in report “*I AM Close Down Report v3.2*”). The experience gained and the lessons learned from this trial that gave rise to the current Intervention, including the creation of the IAM website.

2.2 Requirements Review

.1 Requirements Background

The vision for the second phase of the IAM, of which a website development formed part, was to ensure that all TYA cancer patients in the South West receive the best possible care and support by:

- The development of a bio-psycho-social-vocational domain based framework which integrates assessments, information, care plans, treatment plans, interventions, goal plans, support etc. undertaken with a young person and their support network by the multi-agency professionals who form the team around them during and after their diagnosis and treatment for cancer.
- An explicit acknowledgement that each young person, with his/her support network, is undergoing this journey for the first time and that his/her experience will be individual / novel, requiring person centred, developmentally appropriate, needs-led interventions and support.
- Showing each young person that staff understand they are more than a cancer diagnosis or treatment plan and that all aspects of themselves (reflected in the IAM domains) interact and mutually influence their outcomes and experiences.
- Creating a multimedia platform for partnership working i.e. to capture initial assessment scores, goal based measures, PROMs and PREMS generated for and by the young person with the support of the staff around them.

.2 Objectives

- Develop an assessment system which quantifies the TYA patient’s level of need in each domain, allowing evaluation and analysis of patient needs for individual tracking, service development and the assessment of service interventions.
- Utilise the IAM as a guide for staff engaging with TYA cancer patients to use in order to think holistically about their needs.
- Allow the IAM to be used at MDaT as a framework for discussion of each individual patient’s needs.

2.3 Scope of the Intervention

The key aspects of the Website Development were :

- .1 To develop a multi-use framework based on the domain focused approach (as trialled in phase 1) with the young person at the centre in order to identify and capture the support needs of TYA cancer patients in the South West: all TYA patients in the South West were considered to be in scope as well as all professionals who engage with the TYA population.
- .2 The website should be primarily targeted at TYA patients. It aims to provide them with sufficient information to allow the assessment of their personal situation in a number of “domains” based on a three point colour coded (green, green, amber, red) scale from 0 to 3. However, there is also a need to allow staff access to the patient’s assessment in such a way that the patient remains in control of the release of data entered on the website.
- .3 In addition, it is intended that the site should be a source of information for staff about each domain and the content management capability for the site is a key feature.
- .4 Access to the site should be via individual logon, both for patients and professionals. The logon will control the level of access to elements of the site, although there is also a requirement for the site to provide limited, content only access to site visitors (i.e. without a logon).

2.4 High Level Design

.1 Prioritisation

The development of the IAM website was not originally included in the scope of the On Target Build and Implementation phase, however, this intervention evolved from consideration of a requirement that was prioritised in the original analysis phases of the On Target programme in relation to Physical Wellbeing. From the original design documents, the need for individual 1.2.1 wellbeing sessions were defined as :

“For all TYA’s to have one consultation shortly after diagnosis, shortly before the end of treatment and at a defined time post treatment. Should the patient request/require additional consultation e.g. due to length or change in treatment and post treatment, these will be arranged in order to provide a personalised service tailored to the individual.

TYA nurse specialists are already providing 1.2.1’s at this level however there could be scope to add to these sessions and standardise the practice across the region and across all diagnosis”.

When detailed design work on the 1.2.1 sessions was undertaken, it was identified that a specific focus on Physical Wellbeing, whilst being useful in its own right, might not be a priority for all TYAs. It was concluded that it would be more beneficial to support the development of a holistic assessment which would enable 1.2.1 support to be better focused on the specific needs of the individual concerned. As the IAM project, being run by the TYA Service team, had been piloted in a similar timescale to the On Target design phase it was recognised that there was synergism with the prioritised On Target requirement above. As a consequence, the IAM website intervention was added to the On Target scope via change request 7 which was signed off on 14th August 2014.

.2 Development Overview

The key steps / factors in the development of the IAM Website were :

- a) knowledge and experience gained from the Phase 1 IAM project

- b) developing a simple prototype to support informed discussion on how the website should work
- c) feedback received from a TYA Patient Co-design Event
- d) the look and feel of the Help! Website together with the experience gained from its development
- e) an iterative build process established with the developers (Sitekit) together with their in house website build experience and design capability.
- f) on-going involvement of TYA patients and staff in the development of the website's look, feel and functionality
- g) the development of web page content by selected experts
- h) running User Acceptance Testing after the conclusion of the initial development but prior to the pilot "go-live"
- i) involving the key users of the website i.e. the TYA Nurse Specialists, in the pilot development; providing them with the right equipment to support the new development i.e. iPads; allocating of sufficient time to provide training and guidance

These themes are explored in more detail in the sections below.

3. Intervention Build

3.1 Design and Build Process

.1 Existing IAM Processes

From a technology perspective, the existing IAM process encompasses three key steps :

- completion of the IAM itself
- recording the results from the MDaT
- analysis of the data gathered for all the patients

The last two steps are “back office” processes, i.e. they do not directly involve the patient, and as this project was focused on providing as much patient benefit as possible it was agreed that the scope would be to complete the IAM website i.e. step 1.

An overview of the scope of the processes surrounding the website implementation is contained in Appendix A.

.2 Prototype

In order to provide a visualisation of the website’s possible functionality, a prototype was developed using Powerpoint. Whilst the look and feel of the prototype was not meant to reflect the final website look and feel, the prototype was successful in provoking discussion on functionality and IAM usage.

.3 Codesign Event

A co-design event was held on 23rd June 2014 at the Holiday Inn, Bristol. This was attended by 6 patients and 4 professionals. The feedback provided on the proposed IAM development was very helpful in setting the direction of the website build and the output from this meeting is documented in Appendix B.

.4 Website Look and Feel

Prior to the initiation of the IAM website development, the On Target programme had been working with TYA patients on a psychological support website (*Help!*). The developers chosen to build and host the Help development were Sitekit UK and this collaboration proved to be very successful in delivering a website that was “TYA friendly”. As a consequence of this, it was decided that the IAM development would utilise the same ‘look and feel’ as co-designed for the *Help!* website and that, after an initial build quotation, Sitekit would be the development partners.

.5 User Specification

Following the completion of the co-design event and further internal design discussions, a “user specification” was produced to summarise the requirements for the IAM website. This was signed off on 7th July.

.6 Iterative Build Process

Whilst a specification document was used to convey the requirements of the IAM website to the On Target team and Sitekit, it was acknowledged that converting the requirements into website functions would require on-going “tailoring” as the build

progressed. As such, an iterative process was implemented during construction so that versions of the website were made available as soon as practical to enable feedback to be gathered and amendments made.

To illustrate this, examples of early development versions of the website screens are contained in Appendix C with examples of the finalised screens incorporating the Help “look and feel” being contained in Appendix D.

Weekly tele-conferences were held with Sitekit in support of this build approach.

.7 Key Design Issues

a) Logons

In order that the process of obtaining an IAM logon did not impact on the meetings between the patients and the TYA nurse specialists the decision was made to set-up the IAM logons in advance so that the nurse specialists could allocate a logon to a TYA immediately after introducing the concept to them. A5 Cards were provided to the patients with their individual logon details, and some guidance notes as per Appendix I.

b) Patient confidentiality

To achieve the main goal of producing a patient centric tool, it was believed that one of the key aspects of the build was to put the patients in control of their own data. To this end, it was decided that domain scores would only be released to the TYA Service team under patient control (i.e. via the “send” button on the website). In addition, it was decided that none of the free text comments entered by the patient would be automatically sent to TYA Service and that patients could share further details of their thoughts and feelings at subsequent discussions with their specialist nurse.

c) Enhancement of existing look and feel

The look and feel of the Help! Website previously built by the On Target programme had been developed using co-design principles with much involvement from TYA patients across the south west. As this aspect of the website had been well received in the pilot it was decided to re-use the design principles for the IAM website (see Appendix D).

.8 Content Development

There are ten domains within the IAM namely :

- Physical Wellbeing
- Family, Friends & Relationships
- Education & Work
- Housing, Transport & Finance
- Activities, Hobbies & Social Life
- Drugs, Alcohol & Tobacco
- Sex, Sexuality & Fertility
- Thoughts & Feelings
- Faith, Spirituality & Culture
- My Condition Now

Within the IAM website, each of these domains required information to be included in the following areas :

- Things To Think About
- Key Information

- Other Places To Look

At an early stage in the development, it was identified that the On Target IAM team did not have all the knowledge of each of these areas to develop TYA appropriate content and as a result other professionals were identified and co-opted to develop the necessary material. The use of professionals not directly working on the programme did create some additional dependencies, from a scheduling perspective, and some delays were experienced, although, these were not significant. The developed content was added to the website using Sitekit's standard Content Management System (CMS)

3.2 Timescales and Plan

- .1 The plan as at the end of the pilot is included in Appendix H. The key milestones were :
 - The specification was completed on initial draft 5th June
 final version 7th July
 - The development of the IAM was concluded on 10th November
 - The pilot started on 19th November
 - The pilot concluded on 30th January
- .2 Based on the original plan, this represents a delay of approximately six weeks and the delay arose primarily from issues identified during the development of the website i.e.
 - challenges in translating the requirements into actual website functionality
 - changes to the specification
 - the length of time required to test and re-work elements of the website

The primary cause of these issues was related to the nature of the development itself, in that the website being developed was an innovative product with the translation of the specification into “TYA friendly” features being a particular issue. The evolution of certain of the website features, as per Appendices C & D, reflects the effort required in this area (Appendix E also shows the changes to the design of the IAM “wheel” over the course of the various development phases. Implementing the website into the TYA service environment required more resource than was originally planned e.g. the purchase and set-up of the iPads; defining the procedures surrounding the setting up and distribution of logons etc.

3.3 Co-creation / Co-design

Key elements were :

- the re-use of the co-designed look and feel from the Help website as above.
- the co-design event on 23rd June.
- the development of additional icons by a former TYA patient.
- the on-going involvement of TYA patients in the later stages of the development and the pilot.

3.4 Core Values

In the early stages of the design phase of the On Target programme, all potential interventions were evaluated by the completion of a standardised evaluation framework. This included a series of questions about the core values the programme team felt should be met by all outputs of the programme. It is recognised that these questions derived only from judgements made by the programme team, nevertheless, it is believed that the answers to these questions will assist in establishing the validity and future applicability of the approach taken in the design and delivery of any intervention.

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	Core Values Question	Yes / No**	Comments
1	Can this intervention be offered to all TYA patients?	Yes	
2	Does the intervention ensure that the patient's view / voice is central and acted upon?	Yes	
3	Does this intervention offer sufficient flexibility in its approach so as to meet differences in individual patient wishes?	Yes	
4	Is this intervention evidence based and have we explored other examples of best practice in this area?	Yes	As part of the phase 1 development
5	Does the delivery of this intervention take account of the challenge to patients of dealing with new experiences?	Yes	
6	Will we be able to publicise / promote this intervention in a way that helps to demonstrate the needs of TYA with cancer?	Yes	
7	Will this intervention promote self-management?	Yes	
8	Can this intervention be applied to patients with cancer in other age groups?	Yes	
9	Does the information to be offered about this intervention meet the needs and expectations of TYA / networkers?	Yes	
10	Have TYA / networkers been involved in the creation / design of this intervention?	Yes	
11	Will the delivery of this intervention respect patients' needs for privacy and dignity?	Yes	
12	Does this intervention support the patient as they manage the challenge of cancer to their sense of identity?	Yes	
13	Have we considered all possible ways of delivering this intervention?	Yes	
14	Are there any specific equity / access issues to consider in the implementation of this intervention?	Yes	Access to the internet. iPads were provided to the TYA Nurse specialists to help alleviate this
15	Is this intervention consistent with the future strategic direction of the clinical service and with national policy?	Yes	
16	Will this intervention be applied at the earliest appropriate point after diagnosis?	Yes	
17	Is this intervention applicable / transferable across the SW TYA clinical network?	Yes	
18	Is this intervention sustainable if integrated into the clinical service?	Yes	
19	Have the appropriate teams been engaged in the design of this intervention (or will they be) and are we clear with whom we are taking its further development forward?	Yes	

3.5 Main Deliverables

The key deliverables from this intervention are :

- .1 the IAM website itself (held on a server at the Sitekit UK Data Centre)
- .2 the five iPads issued to the nurse specialists in Truro, Plymouth, Exeter, Bristol & Gloucester
- .3 development products :
 - user specification *IAM Prototype v1.0*

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- prototype *IAM Functional Specification v1.0*

Held on the TYA SW clinical service team drive.

.4 pilot products

- user login cards *IAM Logon Notification v3.0* (see Appendix I)
- pilot results

Also held on the team drive.

4. Pilot review

4.1 Pilot Development & Implementation

.1 Timing

- a) As the IAM website project was added to On Target programme after the main plan set-up, the timescales for the pilot were limited. This, combined with the delays in the development, as per section 3.2.2, meant that limited time was available for the pilot.
- b) The pilot started on 19th November and the analysis of data was based on the information collected as per 30th January.

.2 Location

In order to maximise the number of patients that would have access to the IAM during the pilot period it was agreed that TYA specialist nurses at the PTC and in all the Network Care Centres (Truro, Plymouth, Exeter, Bath & Gloucester) would be involved in the pilot.

.3 Distribution

- a) The website was available at www.tyaiam.co.uk.
- b) Eight logon cards were issued to each centre prior to the launch of the pilot.

.4 Implementation

- a) Appendix F details the process developed to describe how the implementation of the IAM was to proceed following an initial meeting with a TYA patient.
- b) A training day was conducted for the TYA Nurse Specialists at a meeting in Bristol on 1st September 2014. Further implementation discussions re preparation readiness were undertaken via telephone.

.5 Outcome measures

In order to evaluate functionality and relevance for service delivery, the following methods were used:

- a) Website access and utilisation statistics
- b) Direct feedback from users submitted via the website
- c) Feedback from young people via the TYA Specialist Nurses
- d) Informal discussion/feedback at On Target team meetings and with TYA clinical staff
- e) 1:2:1 meetings with the TYA Specialist Nurses
- f) A debriefing session held on the 26th January 2015 with all the TYA Specialist Nurses

4.2 Pilot Review & Outcomes

The pilot finished at 11:59pm on the 30th January. The website remains available for ongoing use in its current form at www.tyaiam.co.uk.

.1 Analytics

Over the course of the pilot 40 logons were given to young people, 72% (n=29) accessed the site and 59% (N=17) submitted one or more IAM.

- a) Qualitative feedback based on returns from TYAs who were approached by the specialist nurses involved in the pilot. This also includes one networker. A full summary can be found in Appendix J.

Theme	Comments
General	Helpful. Useful to express things that are a worry. When young people are not doing it, it's because they can't be bothered, but in concept they think it's good. Found it a bit complicated to understand.
Process	Find it hard to do when not feeling great – it takes a lot of effort – discussed doing it together with a professional would have helped. Mum felt it is easier to be able to do the IAM honestly at home, because it is hard to think clearly about things like finances when you are in 'the bubble' of being in hospital. Some want an opportunity to read through everything before starting the process.
Content	Did not realise the "because" (comments) box was for him (the patient) not the whole team and was not sure what he should put. When choosing the green section it was a bit weird – what/why should he write - he was feeling ok because...

- b) The qualitative feedback below is based on returns from six professionals. A full summary can be found in appendix K.

Theme	Comments
General	Can see great potential when using IAM with young people. Makes the documentation of scores easier. In MDaT we need to ensure we are not questioning patient score. Concerns around (the process) being too much at diagnosis. Thinks really useful post-treatment. Can see applicable for wider age-group, aftercare & networkers. Helps facilitate conversation.
Process	Amount of literature a lot to go through together – but required if the IAM is being done alone. Judgement has to be made on a young person- by-young person basis. Some will require a more collaborative approach. How to remind young people needs to be considered. Time is needed to integrate in to established process for each area. How does it work with e-HNA? Good with ipad – can do together. Will they do it themselves? Need to find right way to present it. Need to ensure feedback is given for submitting.

Content	The prompts are really helpful to normalise and help prioritise feelings/emotions. Will be useful to encourage young people to use free text box. Stepped content. Content good.
Functionality	Difficulties when WiFi is not available. Pop up box keeps popping up if there is an incomplete IAM, despite acknowledging it*. Need notification if an IAM is submitted*. Would be easier to sort young people by hospital in the professionals section*. Need to ensure all aspects of functionality work in each area. Electronic. Easy to use.
Design	The 'things' box displays differently from other sections*. Like the RAG colour ratings.

* As a result of the feedback, a functionality upgrade was authorised on the 22nd January 2015, which rectified these problems (Appendix L).

After the Regional TYA Specialist Nurse meeting on the 26th January 2015, it was agreed that the electronic IAM was to become 'business as usual' i.e. that the use of the IAM should become standard practice with all new patients encountered by the service.

.2 Outcome Mapping

In addition to being mapped against the core values (section 3.4), the project has been mapped against the NHS Outcomes Framework 2014/2015, Macmillan's Nine Outcome Statements and the NICE QS55 quality standards for children and young people with cancer to demonstrate where quality and efficiency gains might lie (Appendix M).

5. Intervention Outcomes

5.1 Intervention Sustainability

Issues include :

- a) On-going costs i.e. maintenance licenses and website hosting costs.
- b) Potential future costs for iPad replacement.
- c) Training as new members of staff are recruited.

5.2 Next Steps

- a) Whilst the data collection for this report concluded at the end of January, the IAM website will remain in routine use within the SW TYA Service. Data from the website will be collected as normal through the existing spreadsheet system.
- b) Following the completion of the On Target programme, funding is being sought for a further service development programme which will seek to enhance the IAM website. Within this proposed programme, a work package will be established to ensure that the current IAM portal is further developed to optimise its functionality; create accessibility by development as an “app”; develop capacity for collecting data relevant to measures of service need; and to enable a final design that offers potential for national dissemination.

6. Acknowledgements

Thanks are due to everyone who helped ensure that the development and pilot were successfully concluded. In particular :

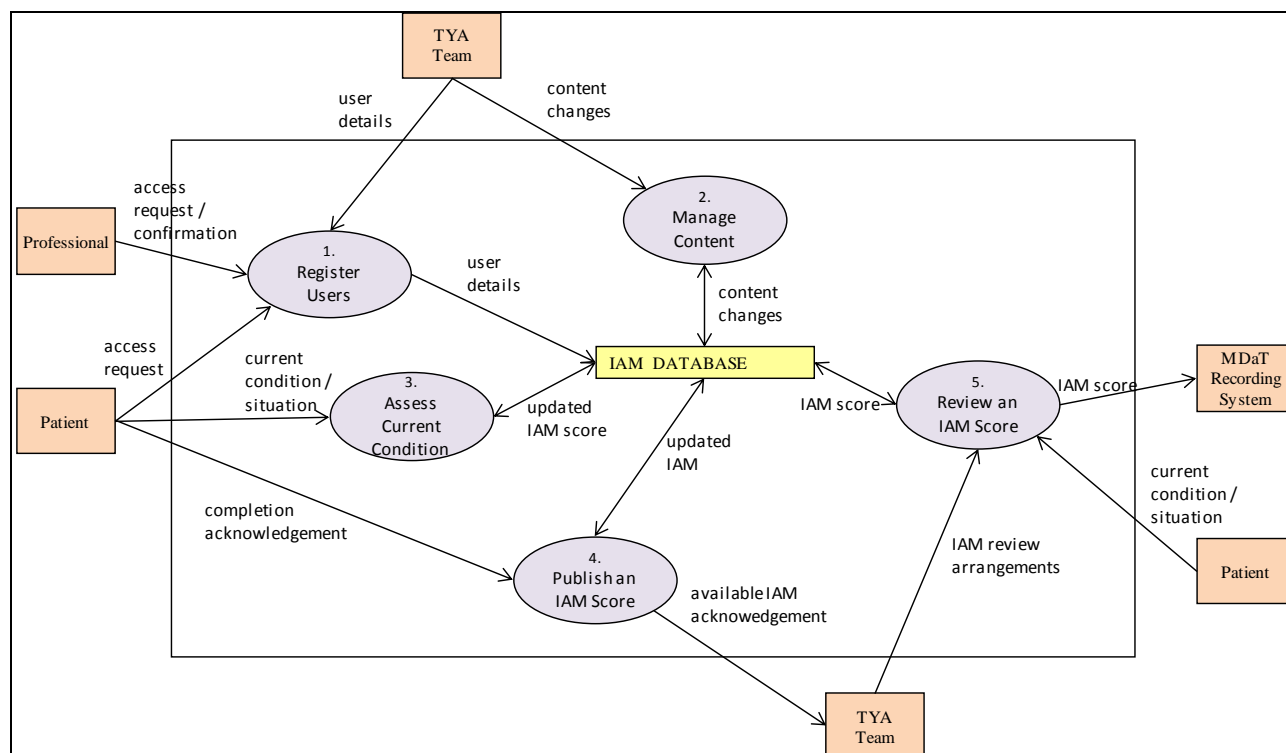
TYA SW Clinical Service Team	Lorraine Beddard
	Vicky Britton
	Alison Cameron
	Jamie Cargill
	Sue Derbyshire
	Sue Dolby
	Hannah Heayn
	Suzie Holmes
	Jax Hulbert
	Sian McKenzie
	Liz Ridgway
	Ellie Ricketts
	Megan Willsher
	Rachel Banks and the CLIC Sargent social workers in the south west

The site specific clinical nurse specialists involved in the care of TYA patients during the Pilot

Everybody who helped with the content development.

Sitekit for the development of the website and Jam the Man for his support with the design of many of the graphics used on the site

Appendix A – Outline Data Flow Diagram



1. Register Users

Users will be registered on the site after verification of their details. Users may be professionals as well as TYA patients.

2. Manage Content

As required the content contained on the site will be refreshed. Content set-up will be limited to specific users. Content may be aimed at professionals or patients and access to the information will be based on the user set-up.

3. Assess Current Condition

The site is primarily aimed at allowing TYA patients to assess their current condition / situation (IAM) in a number of predetermined areas (DOMAINs). Patients will access information for each area as required and then indicate their feelings on a scale of 0 – 3.

4. Publish an IAM Score

When a TYA patient wants to make the details of an IAM available to a professional they will indicate this on the IAM. Notification that this has happened will be sent to the appropriate professional.

5. Review an IAM Score

After the publishing of an IAM score or at an agreed time, the TYA patient and the relevant professional will meet and jointly review of the latest IAM. Once agreed the score will be input into the existing MDaT registration tool.

Appendix B – Co-design Event Feedback

1. Usage / Process

- a) It would be good if the IAM was introduced / demonstrated to the young person fairly early after their diagnosis, although, need to be aware that the amount of information given to patients at this point can be an issue. A card with login details etc. would help, as patients may be put off by having to register themselves before being able to use the site Care should be taken as to who gives this information out. Vicky / Suzie / Jax were suggested as appropriate people. Another option would be to "Try before you register or login" or possibly a login is used to control the complete / save or publish functions.
- b) Some guidelines on the usage of the IAM would be beneficial e.g. frequency of use etc. Some encouragement to fill out all 10 domains, at least on first completing an IAM, was felt not to be too bossy.
- c) A reminder system for the patient might be helpful – e.g. prompts sent to patients at regular intervals (time period to be agreed)
- d) It was felt that the private use of the IAM would be most beneficial on a day to day basis as it would allow the TYA to think about all the issues they are facing and would prepare them for possible future conversations around potentially difficult subjects. It was felt that doing an IAM with family or friends or with a health professional might result in answers that are given in order to meet expectations and therefore not genuine. Follow-up discussions at clinics were also felt to be important to the overall process
- e) It was thought that the IAM would be useful for young people below the TYA age range (15 – 24). Age 10 and upwards was suggested.

2. Scoring and Results Presentation

- a) Need a better definition of the scoring system. Possible solution would be :
 - 0 = no concern; 1 = low concern; 2 = medium concern; 3 = high concern
 - "low" – "high" instead of numbers
 - 1=ok, 2=need more info at next consultation, 3=need more info before next consultationAnother possible solution would be to allow patients to define their own level definitions?
- b) The Level 1 description conveys satisfaction at the amount of information received which isn't the same as describing how a patient might feel. Better wording might be "I feel able to manage without any further support at the moment".
- c) The use of 'immediately' in the level 3 description is misleading. Perhaps re-word to "I would like to be contacted ASAP/ I would like my next appointment brought forward".
- d) Do we remove the information from the descriptions of the different levels and just keep them generic and consistent across all areas?
- e) The system should allow for a blank / zero score this might be in order to reflect that a patient doesn't understand how to score themselves in that domain.
- f) Displaying the results as red, amber and green would allow a clearer visual differentiation on the IAM wheel.

- g) A baseline IAM could be completed to represent how the patient was feeling in each domain before their diagnosis.
- h) When starting a new IAM it might be beneficial for the scores from the previous IAM to be pre-filled so that only the changes need to be input.
- i) When reviewing the IAM on the wheel it would be helpful if the scores could be changed on that page possibly by “clicking” on the wheel itself.
- j) Perhaps there could be a quick scoring method for subsequent use, with a pared down ‘questions to consider’, or have the questions on the same page as the wheel, with links for more information if required.
- k) It would be “user friendly” to be able to page through previous IAM wheels on the same page.
- l) A visual analysis of each domain over time (possibly via a line graph) would be more helpful than trying to create a view of all domains. This facility was felt to be very important to keep, and not just relevant to health professionals.

3. Domains

- a) The “My Diagnosis” domain should represent a longer term view of the patient’s condition and not simply the diagnosis. This could be renamed something like “My understanding of my condition, now”. Two additional areas that could be specifically included in this domain are “Symptoms” and “Fear of recurrence”. The suggestion of renaming it ‘My Cancer’ was considered too frightening for some newly diagnosed patients. Taking ‘My diagnosis’ out altogether was discussed but it was generally agreed that keeping it but renaming it would be the preferred option.
- b) Social Life is not explicitly included in any of the domains and could be best represented in Activities / Hobbies / Interests.
- c) Friends to be included in “Family and Relationships”.
- d) It is quite difficult to understand / quantify what is in “Emotional Wellbeing”. It might be better to rename this “Inner thoughts and feelings”. Any reference to the term ‘psychological’ was felt to be a bad idea, as this term is felt to be too medical.
- e) Culture to be included “Religion / Spirituality” perhaps religion could be renamed “Faith”
- f) Transport (including issues like blue badge etc.) to be included in “Housing & Finance”.

4. Functionality

- a) Publishing the results (i.e. making them available to a keyworker but without generating an email) should be an option. Having the ability to send the results to a keyworker should also be an option. This to include a facility to include a message to the email recipient.
- b) The ability to include free format text on the results and specific to each domain, is desirable. Only the scores and not the text would normally be made available, however, a separate mechanism for releasing the free text may be required for patients who want to do this.
- c) The IAM wheel was felt to be a good way of presenting the results, however, carousel type functionality for selecting the domains might be easier to use when selecting domains. A different selection method could be utilised on a mobile phone, e.g. a grid of colour-coded boxes. But definitely not a list.

- d) Don't include segments within the results wheel i.e. use colours with thermometer type functionality that grows as rating rises from 1-3. The use of colour alone could be an issue with accessibility
- e) The system should not only contain information for infrequent users but should also reflect the needs of frequent users e.g. including a brief definition of each domain on the first domain page rather than having to select "Questions/areas to consider"; making system login as simple as possible; allowing scores to be updated without having to visit all the individual domain pages etc.
- f) The "Online Support" section should be a general information / further reading section.
- g) Contact numbers for urgent / immediate situations should be included e.g. as per the "panic button" on the Help website. Perhaps this could be automatically generated upon 'completing' an IAM if level 3 is scored in multiple / selected domains.
- h) It would be useful if the 'my contacts' section could be populated, perhaps to reflect the scores in each domain.
- i) A quick and easy option to request a 1:2:1 session would be helpful.
- j) It would be helpful if an IAM website link could be loaded onto the ward iPads, although, there should be no compulsion to complete it.
- k) Delivering to a mobile device as an "app" would be great

5. Privacy / Data Security

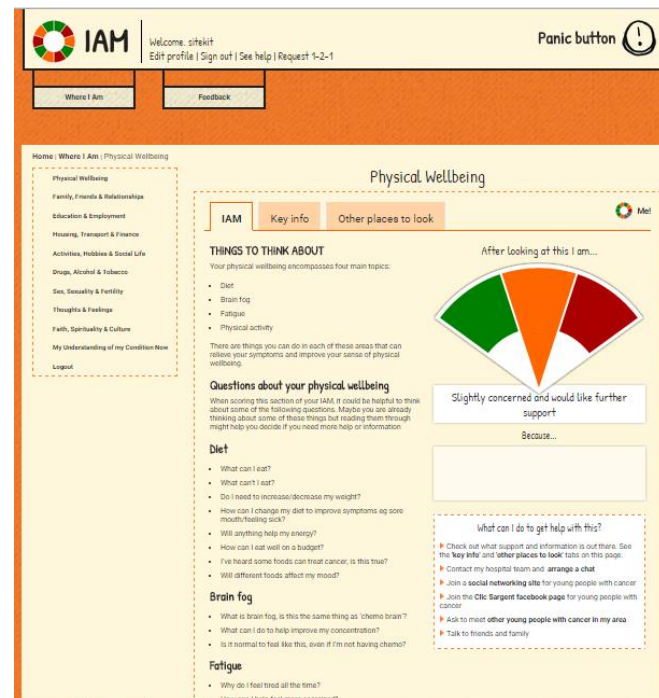
- a) Need to be clear who has access to the data and who will receive the email that is generated upon publishing the results i.e. will the email go to a generic address or a specific person? The service levels for response to emails will need to be defined e.g. how quickly will it take to respond to the patient ?
- b) Discussions of the disclosed data in clinics will need to take account of the presence of family / friends / carers.

Appendix D – Sample Finalised Website Screens

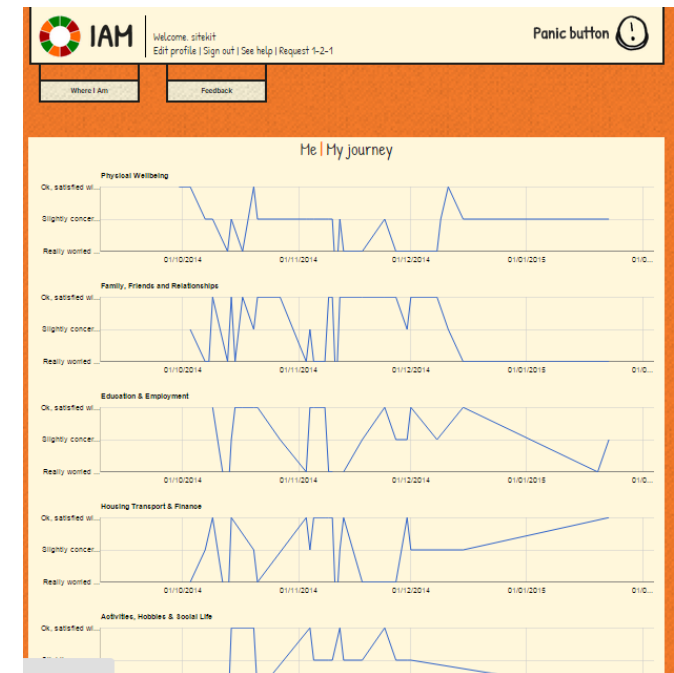
IAM Wheel



Domain Screen

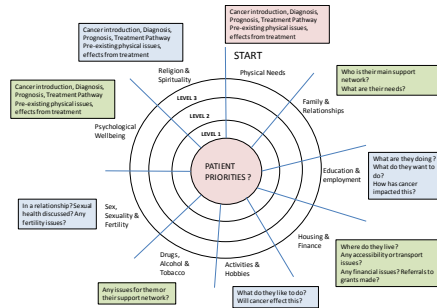


My Journey

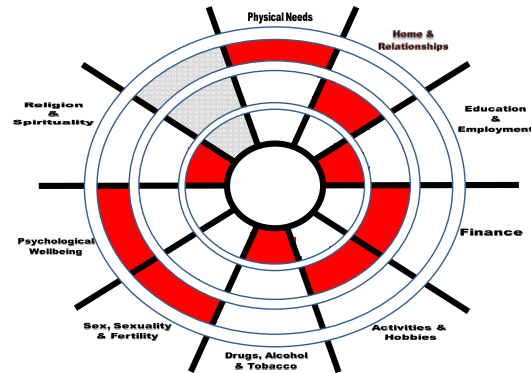


Appendix E – IAM Wheel Development

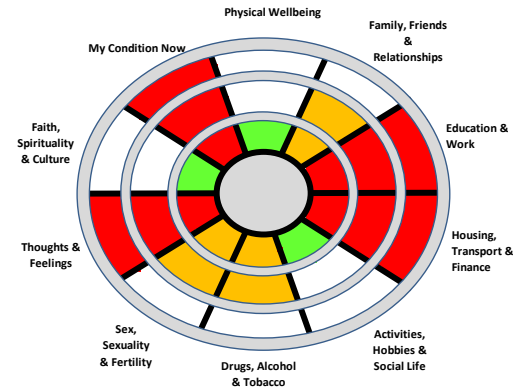
1. Initial Concept



2. Initial IAM Wheel



3. Revised IAM Wheel



4. IAM Prototype



5. Implemented IAM Wheel

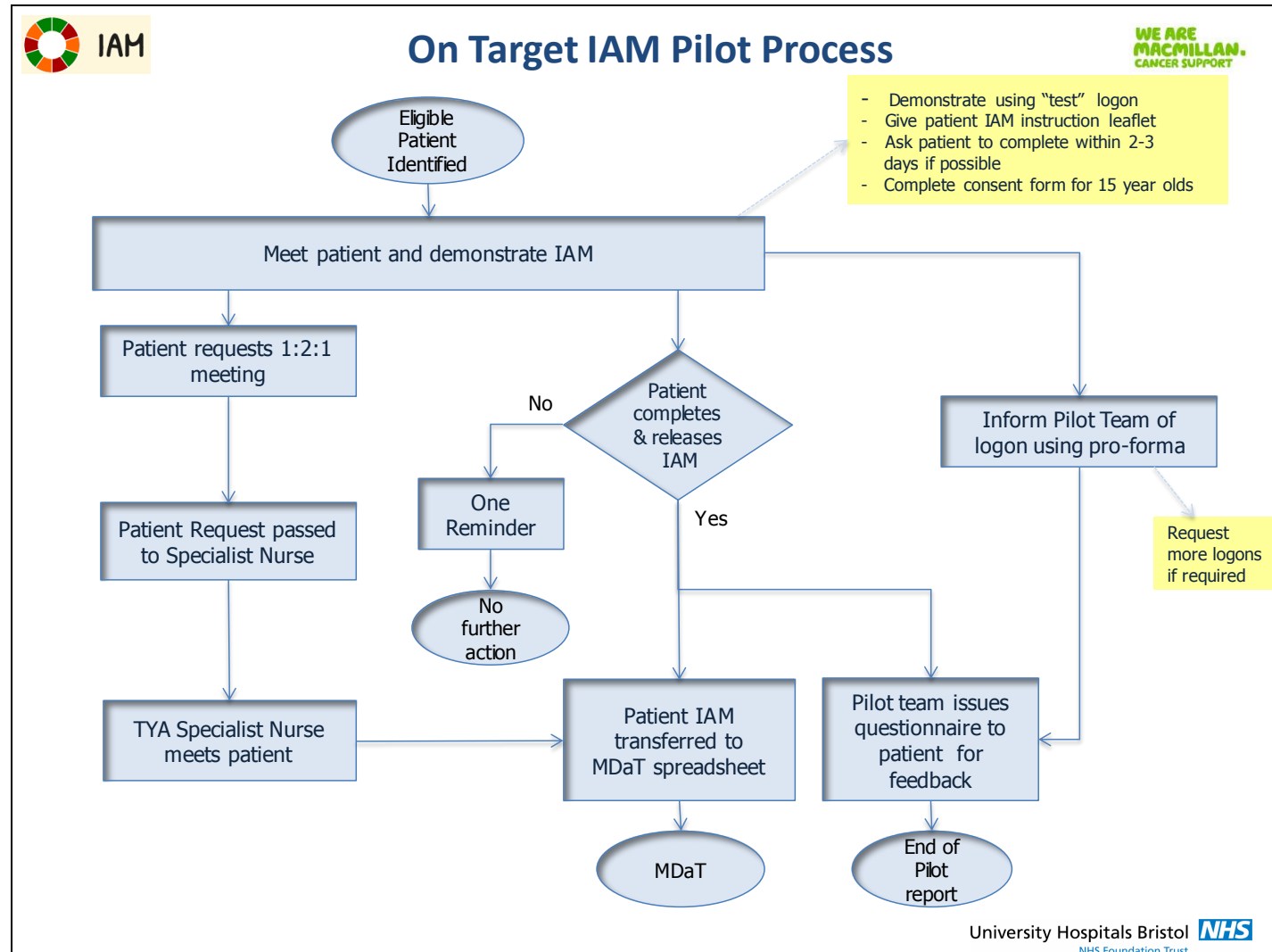
Circle View



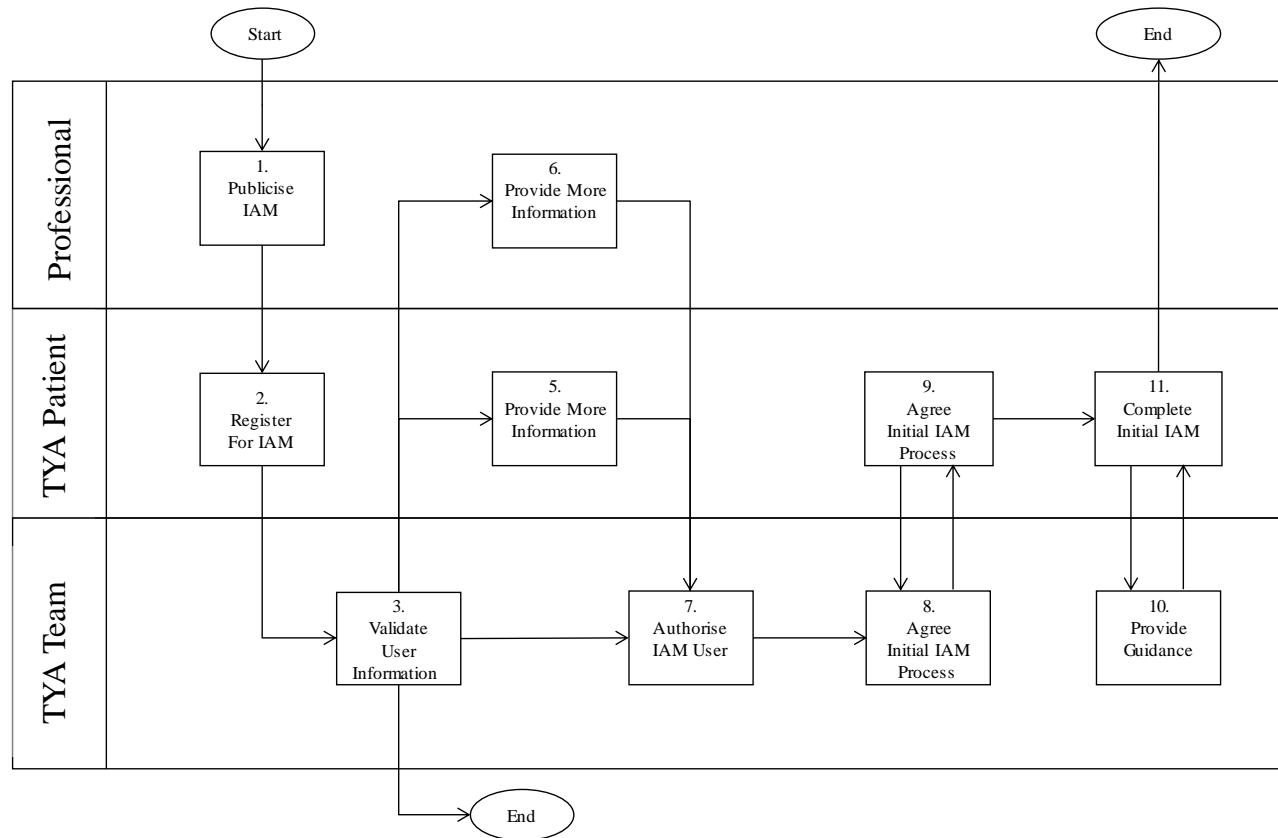
Table View

Friday 23 Jan. 2015	
Physical Wellbeing	<input type="radio"/> <input type="radio"/> <input type="radio"/> Slightly concerned and would like further support
Family, Friends & Relationships	<input type="radio"/> <input type="radio"/> <input type="radio"/> Really worried and in need of support
Education & Employment	<input type="radio"/> <input type="radio"/> <input type="radio"/> Slightly concerned and would like further support
Housing Transport & Finance	<input type="radio"/> <input type="radio"/> <input type="radio"/> OK, satisfied with the information I have.
Activities, Hobbies & Social Life	<input type="radio"/> <input type="radio"/> <input type="radio"/> Really worried and in need of support
Drugs, Alcohol & Tobacco	<input type="radio"/> <input type="radio"/> <input type="radio"/> Slightly concerned and would like further support
Sex, Sexuality & Fertility	<input type="radio"/> <input type="radio"/> <input type="radio"/> OK, satisfied with the information I have.
Thoughts and Feelings	<input type="radio"/> <input type="radio"/> <input type="radio"/> OK, satisfied with the information I have.
Faith, Spirituality and Culture	<input type="radio"/> <input type="radio"/> <input type="radio"/> Really worried and in need of support
My Understanding of my Condition Now	<input type="radio"/> <input type="radio"/> <input type="radio"/> OK, satisfied with the information I have.

Appendix F – IAM Process for TYA Nurse Specialist

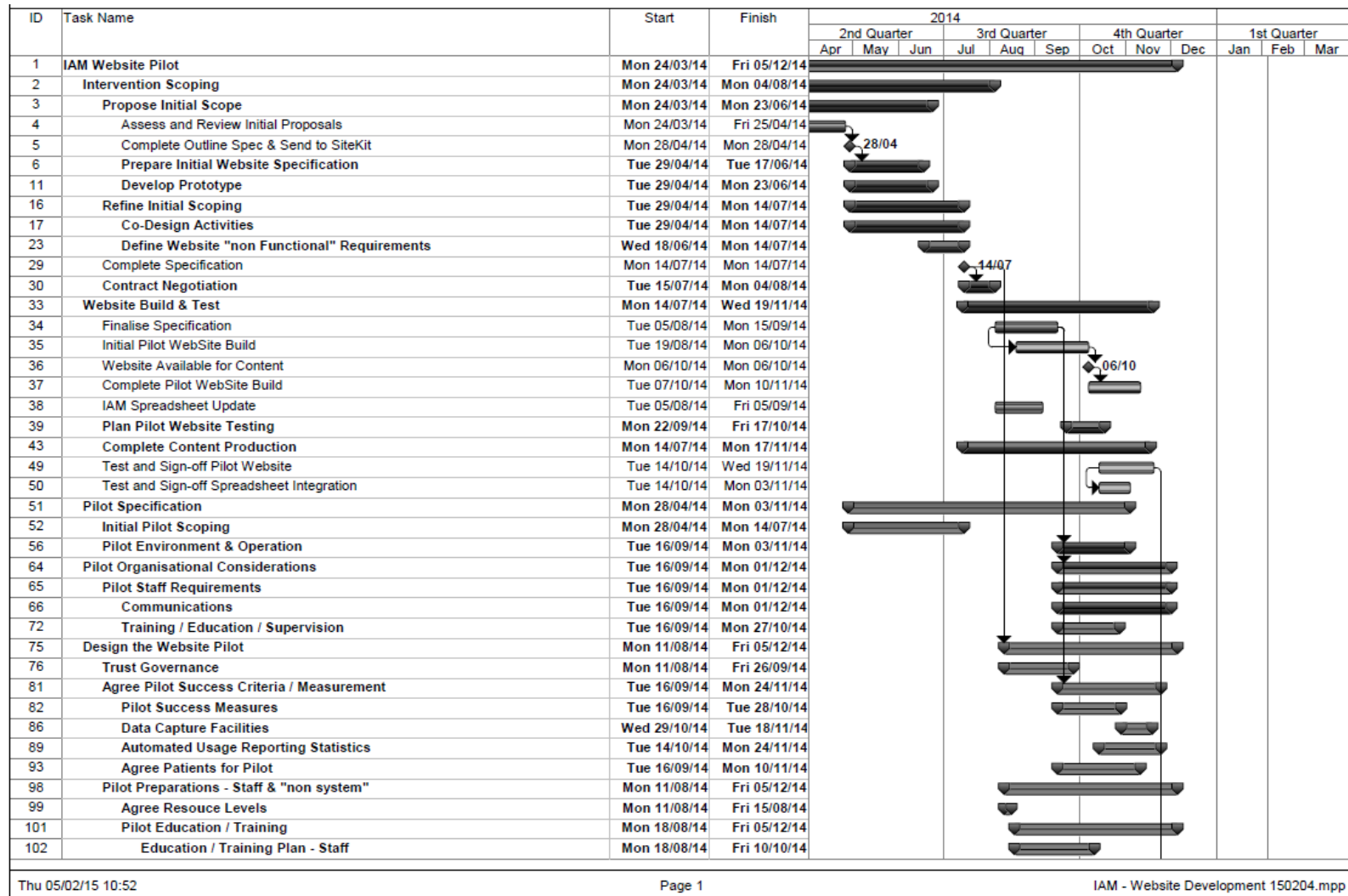


Appendix G – IAM Registration Process

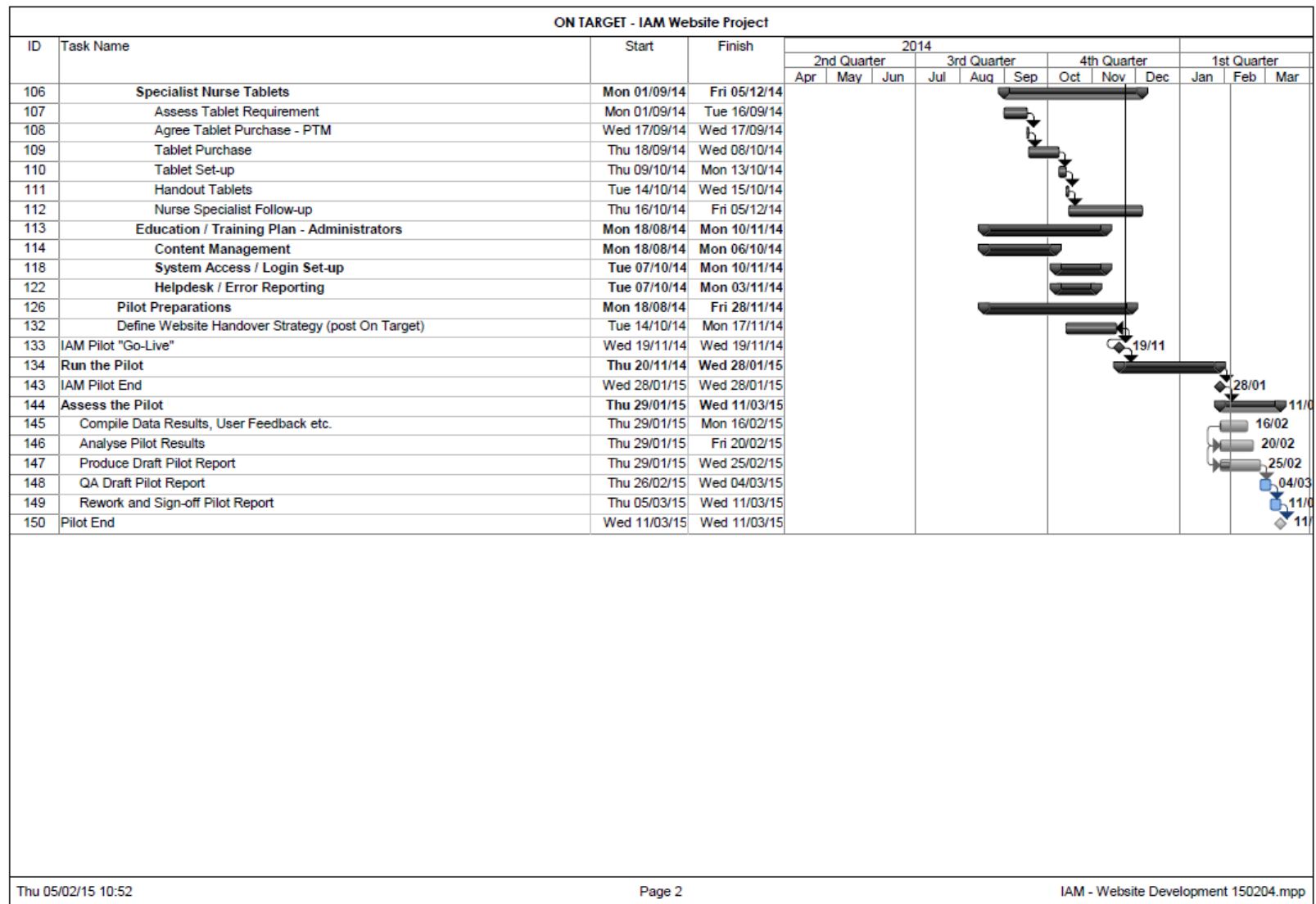


IAM Website – Intervention Report

Appendix H – Project Plan



IAM Website – Intervention Report



Appendix I – Logon Cards



The logon card has a green-to-red gradient background. At the top center is the IAM logo, which consists of a circular icon with colored segments and the letters 'IAM' to its right. Below the logo, the website address www.tyaiaim.co.uk is displayed in large, red, outlined text. Underneath, the text 'Your Logon for IAM is :' is shown in white. This is followed by the 'Userid : Z99IAM' and 'Password : xxxx99' in white text. A paragraph in white text asks the user to complete the IAM as discussed with their Nurse Specialist and see if it's helpful to you, with a note that brief instructions on how to use the site are on the reverse of this card. Another paragraph in red text asks the user to provide feedback on what was good and what was bad, plus any suggestions to improve the site, with a link to www.ontargetteam.uhbristol.nhs.uk. The bottom of the card features a footer with several logos and icons: a circular icon with a '5' and '20%' on the left; a 'Pick a colour' section with five colored circles (green, red, orange, blue, purple); a 'Night switch' icon; and a row of logos including 'ON TARGET', 'TYA Care', 'WE ARE MACMILLAN. CANCER SUPPORT', 'University Hospitals Bristol', and 'NHS'.



www.tyaiaim.co.uk


Your Logon for IAM is :

Userid : Z99IAM

Password : xxxx99

Please complete the IAM as discussed with your Nurse Specialist and see if it's helpful to you.
(brief instructions on how to use the site are on the reverse of this card)


Then tell us what you think about it (what was good and what was bad) plus any suggestions you might have to improve the site
(www.ontargetteam.uhbristol.nhs.uk)

 Pick a colour      Night switch 

HOW TO ENTER YOUR IAM


1. Select the icon on the wheel you wish to score e.g. Family, Friends & Relationships



5. To return to the IAM wheel, select the "Me" icon and repeat the scoring process

2. For the selected icon, read 'Things to Think About' to help you to score yourself.


3. Select the appropriate score for you by clicking on the red, amber or green segment



4. Enter you're thoughts about your score here if you wish

OTHER FEATURES


To request a meeting with a member of the IAM team select 'Request 1:2:1'



'My Journey' graphically displays your scores over time

The 'Where I AM' area will store all your scores and allow you to page through all your IAMs using next / previous

Customise the website by selecting a colour or a "night view"



'Send' will enable the TYA team to see the scores (but not your comments)

Appendix J– Qualitative feedback – Young People

Who	How	Comments	Theme	Action
YP	via TYASN/website	Found it helpful	General	N/A
YP	via website	It was useful to express things that were worrying them.		N/A
YP	via TYASN	Much of the feedback from patients, is that they 'just haven't' done the IAM, but in concept it's good.		Investigate
YP	via TYASN/website	Patients have seemed keener to do the assessment themselves and then not actually done it, so far the only feedback on this was that I just haven't got around to it yet.		Investigate
YP	via TYASN	Found it a bit complicated to understand at first.		Investigate
YP	via TYASN	Find it hard to do when not feeling great – it takes a lot of effort – discussed doing it together with a professional would have helped.	Process	Investigate
Networker	via TYASN	They thought it would be easier to do the IAM honestly at home, because it is hard to think clearly about things like finances when you are in 'the bubble' of being in hospital.		N/A
YP	via TYASN	Some want an opportunity to read through everything before starting the process.		Investigate
YP	via TYASN	Did not realise the 'because' box was for him not the whole team and was not sure what he should put.	Content	Event item
YP	via TYASN	When choosing the green section it felt 'a bit weird' to then write in the comments box – what/why should they write?		Event item

Appendix K – Qualitative feedback – Professionals

Prof	via website	Can see great potential when using IAM with young people.	General	N/A
Prof	face to face	Makes the documentation of scores easier.		N/A
Prof	face to face	In MDaT we need to ensure we are not questioning patient score.		Investigate
Prof	face to face	Concerns around being too much at diagnosis.		Event item
Prof	face to face	Thinks really useful post-treatment.		N/A
Prof	face to face	Can see applicable for wider age-group, aftercare & networkers.		Investigate
Prof	face to face	Helps facilitate conversation.		N/A
Prof	via website	Amount of literature a lot to go through together – but required if the IAM is being done alone	Process	Investigate
Prof	face to face	Judgement has to be made on a young person- by-young person basis.		N/A
Prof	face to face	Some will require a more collaborative approach		Investigate
Prof	face to face	How to remind young people needs to be considered		Investigate
Prof	face to face	Time is needed to integrate in established process for each area		Investigate
Prof	face to face	How does it work with e-HNA?		Investigate
Prof	face to face	Good with ipad – can do together		N/A
Prof	face to face	Will they do it themselves? Need to find right way to present it	Content	Investigate
Prof	face to face	Need to ensure feedback is given for submitting		Event item
Prof	face to face	The prompts are really helpful to normalise and help prioritise feelings/emotions		N/A
Prof	face to face	Will be useful to encourage young people to use free text box		Event item
Prof	face to face	Stepped content		Investigate
Prof	face to face	Content good		N/A
Prof	face to face	Difficulties when WiFi is not available		Investigate offline options
Prof	face to face	Pop up box keeps popping up if there is an incomplete IAM, despite acknowledging it*	Functionality	Upgrade
Prof	face to face	Need notification if an IAM is submitted*		Upgrade
Prof	face to face	Would be easier to sort young people by hospital in the professionals section*		Upgrade
Prof	face to face	Need to ensure all aspects of functionality work in each area		Monitor
Prof	face to face	Good that it's electronic		N/A
Prof	face to face	Easy to use		N/A
Prof	face to face	The 'things' box displays differently from other sections	Design	Sorted
Prof	face to face	Like the RAG colour ratings		N/A

Appendix L – Pilot Functionality Upgrade

Sitekit Health Ltd
 Sitekit House
 3 Broom Place
 Portree
 Isle of Skye
 IV51 9HL
 VAT Reg No: 108265034
 Company Reg No: SC 376978



Invoice

Page 1

FAO - J Cheshire
 On Target
 Bristol Haematology and Oncology Centre
 Horfield Road BRISTOL
 BS2 8ED

Invoice Number 549
Tax Date 22/01/2015
Your PO Number OT-201415-161
Customer Code UHBRN1
Our Reference 2756

Details

Development time at request of J Cheshire
 6.5 hours at £80 plus vat
 from contingency pot of £3,000

Quantity	Rate	VAT	Net Amount
6.50	80.00	104.00	520.00

You may pay this invoice by BACS - please quote the invoice number within your payment.

Account Name: Sitekit Health Ltd
 Account Number: 06004547
 Sort Code: 80-09-47

If you have any queries about this invoice please email - finance@sitekit.net or ring 0845 299 0900

Payment Terms: 30 days

Total Net Amount	£520.00
Total VAT Amount @ 20%	£104.00
Invoice Total	£624.00

Appendix M – Outcome Mapping

WORKSTREAM:		IAM	
INTERVENTION:		IAM Website	
CORE VALUES QUESTIONS		YES / NO	Brief explanation if required
1	Can this intervention be offered to all TYA patients?	Y	
2	Does the intervention ensure that the patient's view / voice is central and acted upon?	Y	
3	Does this intervention offer sufficient flexibility in its approach so as to meet differences in individual patient wishes?	Y	
4	Is this intervention evidence based and have we explored other examples of best practice in this area?	Y	
5	Does the delivery of this intervention take account of the challenge to patients of dealing with new experiences?	Y	We need to ensure that there is sufficient introduction to the IAM by way of personal introduction and text explanation within the content
6	Will we be able to publicise / promote this intervention in a way that helps to demonstrate the needs of TYA with cancer?	Y	
7	Will this intervention promote self management?	Y	
8	Can this intervention be applied to patients with cancer in other age groups?	Y	
9	Does the information to be offered about this intervention meet the needs and expectations of TYA / networkers?	Y	Based on initial work identifying patients' needs
10	Have TYA / networkers been involved in the creation / design of this intervention?	Y	
11	Will the delivery of this intervention respect patients' needs for privacy and dignity?	Y	We will need to ensure there is sufficient security within the system.
12	Does this intervention support the patient as they manage the challenge of cancer to their sense of identity?	Y	
13	Have we considered all possible ways of delivering this intervention?	Y	Based on work done previously by the TYA Service team
14	Are there any specific equity / access issues to consider in the implementation of this intervention?	Y	Those with no computer access or physical impairments that prevents computer use.
15	Is this intervention consistent with the future strategic direction of the clinical service and with national policy?	Y	
16	Will this intervention be applied at the earliest appropriate point after diagnosis?	Y	The plan is for the TYA Specialist nurses to introduce the patient to the IAM following diagnosis
17	Is this intervention applicable / transferable across the SW TYA clinical network?	Y	
18	Is this intervention sustainable if integrated into the clinical service?	Y	Will require ongoing maintenance of website and contents updated
19	Have the appropriate teams been engaged in the design of this intervention (or will they be) and are we clear with whom we are taking its further development forward?	Y	

WORKSTREAM:		IAM	
INTERVENTION:		IAM Website	
APPLICABILITY TO		YES / NO	Brief explanation for answer
1	I was diagnosed early	N/A	
2	I understand, so I make good decisions	Y	The IAM is designed specifically to help patients assess their needs in many different areas so they can make decisions about the extra support that they may need.
3	I get the treatment and care which are best for my cancer and my life	Y	The IAM will focus on the 'best treatment for my life'.
4	Those around me are well supported	Y	The 'family and relationships' domain should provide access to support for networkers
5	I am treated with dignity and respect	Y	This is making the patient's voice central in determining their own support and help, but also providing advice and guidance from health professionals.
6	I know what I can do to help myself and who else can help me	Y	This is the primary focus of the IAM
7	I can enjoy life	Y	Again, this is one of the primary roles of the IAM
8	I feel part of a community and I'm inspired to give something back	?	
9	I want to die well	N/A	