

**Operational research  
report following visits and  
analysis of Gender  
Identity Clinics in England**



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**Operational research report following visits and analysis of Gender Identity Clinics in England: Exploring models of care, patient flow and resilience under growing demand**

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## 1 Executive summary

The operational research within this report was conducted by a senior operational researcher from the then Chief Analysts Team within NHS England. It was commissioned by the Gender Identity Task and Finish Group (TFG), convened as part of Specialised Commissioning within NHS England. Six out of seven Gender Identity Clinics were visited during Quarter 4 of 2014/15 (Exeter, London, Newcastle, Sheffield, Nottingham and Leeds). Discrete even simulation models were constructed to test and illustrate the observations made during the clinic visits. [Clinic descriptions in sections 4-9 and modelling in section 10]

The key objectives of the research were to:

- 1) Describe the clinical models operated by each GIC;
- 2) Estimate the impact on waiting times of the growth of demand;
- 3) Using theoretical clinic models test and illustrate observations and the likelihood of meeting RTT given growth in demand.

These objectives have the aim of providing an evidence base that the TFG and the Clinical Reference Group (CRG) can use to help the service meet the RTT standard and reduce current inequalities in access.

The methodology applied was a fusion of soft operational research methods and quantitative discrete event simulation. There were a series of models built following the clinic visits. This methodology was chosen in order to facilitate the description of the patient pathway at each clinic and then build a patient level model of flow through hypothetical pathway, being able to assess resources and queues in systems that have the characteristics observed.

As with any modelling, the limitations are in what is excluded from the process in order to make the model finite or 'framed.' In addition, the modelling is naturally biased to a point in time. That is, the process as described during the visit and the data that was available at the time. Missing data and information has been estimated and as a result the scenarios tested are gross in order to overcome the level of error that such estimation incurs. [Description of methodology in section 3]

To note: although the methodology used is standardly applied to industrial processes it can be used to understand any situation involving queues and bottlenecks, helping services to question where delays are occurring and so improve the patient pathway and, hopefully, experience and outcomes. During the evidence gathering phase, it was possible to view patient experience data (See Annex 4 for London Clinic Patient Experience data), which tended to be very positive, but there was no consistent outcome data defined or available.

### 1.1 Observations

The six clinics are operating six differently good patient pathways that seek to meet the needs of patients with gender dysphoria. There is a high degree of innovation across the clinics but there is little sharing of this innovation.

In 2014/15 there were around 215<sup>1</sup> patients referred per month to the service. It is not clear whether these are unique patients or whether there is a practice of making multiple referrals given the variation in waiting times. The total waiting for first appointments was 2377<sup>2</sup> people in January 2015 of which 1296 (55%) were on the waiting list for London and 103 (4%) were on the waiting list for Sheffield. The total population for all clinics in January 2015 was 5995<sup>3</sup> of which 3450 (58%) are in the patient population at the London clinic and 254 (4%) are in the clinic population at Sheffield. Average waiting times for first appointment show inequalities in access as they vary from 69<sup>4</sup> weeks (Leeds) to 9 weeks (Northampton) for patients receiving their first appointment in the period October 14 – January 15.

There are no accredited/regulated training posts for clinicians working in Gender Clinics. Training is by “apprenticeship” and any GIC that increases its clinical complement offers such apprenticeships. There are very few training places: Nottingham had a registrar on rotation and the conversion rate to consultants in the field is not clear.

Data was hard to come by for the majority of the clinics visited and in a non-standard format.

## 1.2 Key findings

The different approaches to delivering patient care were more or less vulnerable to situations outside of their control. The obvious situation outside of the clinics’ control is surgical waits, and clinics delivering the same level of care to newly referred patients as to those patients waiting for surgery, who are the most vulnerable to losing capacity to take on new patients when surgical waits increase.

Likewise clinics with double handled appointments or processes, where an appointment or task requires simultaneous attention of more than one clinician (such as MDTs, joint review appointments and workshops) can be vulnerable to generating unintended backlogs. However, this needs to be balanced with the benefit that these approaches have to the patient and the quality of their care.

These findings have been verified by theoretical models presented in section 10.

Triage and streaming have both been applied by different clinics at different stages of the pathway and have been effective in targeting resource and directing self-care or preparation amongst patients.

## 1.3 Recommendations

- 1) That clinics share innovation and consider adoption where appropriate and after suitable evaluation;

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<sup>1</sup> Figure approximated from FOI responses <http://uktrans.info/waitingtimes> [accessed 13:48 02/07/2015]

<sup>2</sup> ibid

<sup>3</sup> ibid

<sup>4</sup> ibid

- 2) That the points in the pathways that currently require double handling be reviewed in the light of rising demand within the bounds of good practice and benefit to patient care;
- 3) If it is intended to meet demand, then growing the workforce should be a high priority and be planned to exceed succession planning. This could be achieved through growing existing sites or opening further GICs;
- 4) That measures of success are developed for the service so that quality and patient outcomes and their impacts can be clearly demonstrated;
- 5) That the service plans for increasing complexity in their patient base (including co-morbidities and co-existing conditions);
- 6) That the service agrees a core set of management information [Annex 3] and considers whether it should report to standard data collections such as HES Outpatients<sup>5</sup> and Unify2 RTT<sup>6</sup>. This should seek to highlight areas to improve to reduce inequity in access and outcomes.

## 1.4 Conclusions

This piece of research is the first time that all clinics handling a significant volume of referrals have been visited and their processes described. It is our reflection that this work could be built on through the CRG and that whilst uniformity of service may not be desirable, it is possible for the different clinics to exchange their practice and standardise information data and outcomes reported.

Considering the recommendations could enable further optimisation of the service with greater transparency of its performance and achievements and greater resilience and capacity to achieve RTT in the future, which will lead to shorter waits for patients.

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<sup>5</sup> <http://www.hscic.gov.uk/hes> [accessed 13:31 27/10/15]

<sup>6</sup> <https://www.england.nhs.uk/statistics/statistical-work-areas/rtt-waiting-times/> [accessed 13:34 27/10/2015]



## 2 Introduction

The research within this report was conducted by a senior operational researcher from the then Analytical Insights and Resource Unit within NHS England. Six out of seven Gender Identity Clinics were visited during Quarter 4 of 2014/15 (Exeter, London, Newcastle, Sheffield, Nottingham and Leeds).

The key objectives of the research were to:

- 1) Describe the clinical models operated by each GIC
- 2) Model and run scenarios for the clinics to assess vulnerabilities to not meeting Referral to Treatment standard (RTT), impact of increasing workforce , expected growth in demand and of doing nothing

These objectives have the aim of providing an evidence base that the TFG and the Clinical Reference Group can use to help the service meet the RTT standard.

The following section outlines the methodology applied, which was a fusion of soft operational research methods and quantitative discrete event simulation. There were a number of theoretical models built representing the observations made and a hypothetical clinic. This section also describes the limitations of the modelling approach.

Section 4 – 9 describes the schematic of the patient pathway and the available data for each. Where possible the pathways described have been compared to the nationally agreed standards CR181 which is based on WPATH v7, which can be found in Annex 2.

Section 10 describes the modelling done and gives results.

Section 11 discusses a range of recommendations, suggestions and conclusions. Annex 3 contains a “starter for 10” minimum dataset and possible management information metrics.

## 3 Methodology

### 3.1 Introduction

The research conducted had two phases: the visiting of each clinic and the modelling of observations. The remainder of this section outlines the visit methodology, the modelling methodology and the limitations of the approach.

### 3.2 Visit methodology

The visit methodology comprised two strands of soft operational research (OR), which were then evidenced with data. Soft OR typically describes techniques related to problem structuring and systems modelling that may follow a grammar or a set of rules but do not involve the use of hard data in getting to their output. The outputs were then evidenced with data.

#### 3.2.1 Narrative

The first approach was that of narrative: simply encouraging one or two clinicians to describe how patients flow through their care pathway. This involves use of open questions, generalisations and exceptions and a “what happens next” approach.

#### 3.2.2 Shared display

Coupled with the narrative is the use of shared display, a surface that all contributors can see and influence. Mostly, we used A3 paper but white/smart boards are also very popular in this methodology. However, given the itinerant nature of the project we used something more portable. During the narrative we illustrated the patient pathway as a simple flow diagram noting the different resources required at each appointment and their duration and frequency. Some clinics had already prepared a patient flow diagram and so the questions were around exceptions, resources, durations and frequency.

The use of a shared display meant that the clinicians could correct errors or add enhancements to the patient pathway, which in turn led to a closer approximation being achieved in the first pass. This was valuable because each clinic was only visited once for less than a day.

#### 3.2.3 Evidenced with data

In some approaches it is enough to describe the patient pathways but in order to proceed to discrete event simulation modelling the patient pathway was evidenced with data.

The clinics were asked to supply to evidence the queries below:

- i. The patient pathway through the service
- ii. The types of service accessed on this pathway and the typical duration and frequency of engagement
- iii. Which services are accessed in series or in parallel

- iv. Which services may be accessed at the treatment setting, more locally to the patient or a combination of the two
- v. What the perceived blockages are and what feedback there is available from patients about their experience of the service
- vi. What services a patient accesses once they have been assessed to proceed with genital reconstruction surgery and their frequency of engagement
- vii. Which services, therapies or treatments may be funded locally or by the clinic, whether this funding is block, tariff or bundled with something else
- viii. The composition of the patient population in terms of time since referral, time since first appointment, time since decision to proceed with genital reconstruction surgery, types of services currently accessed, duration and frequency of access
- ix. The outcomes other than genital reconstruction surgery and the proportion of patients who choose those, including anyone who then re-accesses the clinic seeking an alternate choice or further support at a future date

In addition, where a clinic's pathway was not wholly covered by this data, more data was requested and used to explore the patient flow through the pathway as described.

### 3.3 Modelling methodology

Modelling was completed using a software package called Simul8<sup>7</sup> and a technique called discrete event simulation. This approach describes the world as a system of workstations and queues through which components or products travel until they are completed. Typically, it is used to model assembly lines and customer service situations such as call centres. However, it has been used extensively in the health sector where waiting times and processes are of increasing interest<sup>8</sup>.

Developing these models has had 8 steps: understanding the problem; sketch; resource application; patient arrival rate; calibration; warm up period; data collection period and analysis of key indicators

#### 3.3.1 The problem

The first stage of building the model is understanding the problem that needs to be addressed. It is possible to build many models of the same system to answer many different problems. The problem identified was around the 18 week access targets for Gender Identity Clinics and the impact of surgical delays on the capacity of the clinic. The wider issue was around understanding the different clinical models operating in the different clinics.

#### 3.3.2 Sketch

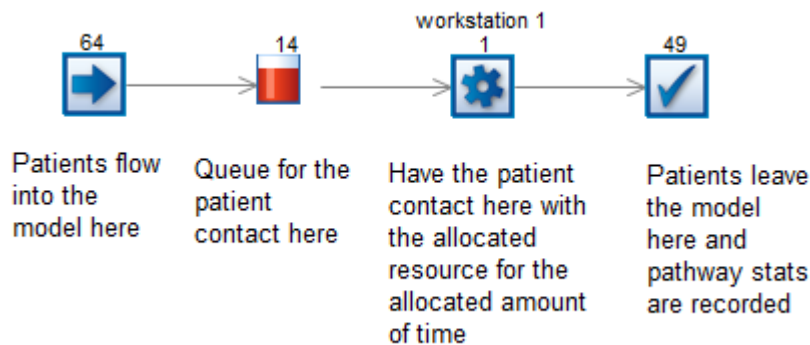
The next stage is to complete a sketch of the patient pathway. In the context of this project, this phase was completed during the initial meeting. The sketch is then transferred into the software where "dummy" workstations may need to be added to make the software work. These are work-arounds and do not take resource or time. An example of this would be a workstation where the patient is referred to more than

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<sup>7</sup> <http://www.simul8.com/> [accessed 13:38 29/06/2015]

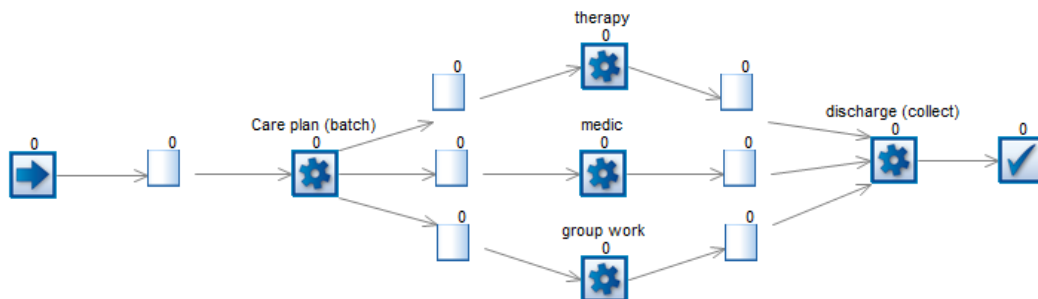
<sup>8</sup> <http://simul8healthcare.com/> [accessed 14:01 29/06/2015]

one service at once, which is a batching process, and, when all treatment is complete, the workstation that collects all the patient's activity together prior to discharge, which is a collecting process.



*Figure 3.1: A simple model of a patient pathway showing inflow, queues, workstations and outflow*

Figure 3.1 shows a very simple patient pathway model where 64 patients have entered the model, 14 are queuing for a patient contact, the 1 patient in the workstation (the box with a cog in it) and 49 patients have completed the pathway. Statistics are produced for patients that have completed the pathway.



*Figure 3.2: A more complex model of a patient pathway showing inflow, queues, workstations and outflow and also batching and collecting a patient*

Figure 3.2 shows a more complex pathway where an individual patient is batched at the care planning stage and undergoes three simultaneous treatments. They are then collected at the discharge phase. During batching it appears that there are three times as many people in the model as there should be but this is because the patient has effectively been divided in three and then will be collected back into one patient before discharge.

### 3.3.3 Resource application

When the outline sketch of the model is complete, the resources available at the clinic are then applied to the model. This is done by specialty, whole time equivalent and an estimation of patient facing time. For example, a clinic may have two whole time equivalent therapists who spend 75% of the time in patient facing activity.

### **3.3.4 Patient arrival rate**

The patient arrival rate is set as the number of hours between patients presenting as new referrals. This is set up with some random variation to simulate the actual way that referrals come in. It varies between clinics as clinics receive different numbers of referrals per year.

### **3.3.5 Warm up period**

The model starts running from “empty” that is as if the clinic has just opened for the first time. It needs a warm up period in order to get to a steady state. This was typically around seven years. To start with patients get through the care pathway in the minimum time with no wait to be seen. As the model warms up queues form and a more realistic patient pathway time is generated. This is a relatively long warm up period but reflects the complexity of some of the patient pathways and the length of time that people can be in the system especially on the F2M pathway where four surgeries might be required in addition to stabilisation of hormone treatment.

### **3.3.6 Data collection period**

The data collection period is set to a duration over which a baseline can be established and the scenarios tested. This is also governed by the complexity of the pathway and the time taken or waited for activities. Again seven years was used. Results are presented as the average of all patients finishing their pathway during the data collection period.

### **3.3.7 Calibration**

Calibration is the process of adjusting the model to fit the data supplied. Typically very small adjustments in the underlying assumptions will bring the model in to line with the management information. However, the models presented here are theoretical and it matters that the models are consistent with each other rather than aligned to one particular clinic.

### **3.3.8 Analysis of key indicators**

For each scenario that is run a key set of indicators is analysed:

- 1) The average time waited before first appointment
- 2) The average time in the pathway once first appointment has occurred
- 3) The average number of each specialty appointments per patient

In addition the modelling gives utility of each resource and judgements can be made about how sustainable those levels of utility are. In addition, the calibration process gives an idea of the most influential variables in the model and how sensitive the model is to changing these variables. This can also inform the analysis and lead to conclusions about the robustness of the system.

## 3.4 Scenario generation

In addition to the two observations that were modelled, (double handled appointments and in the impact of surgical waits) a whole clinic model was used to illustrate the workforce requirement to meet the growth in demand being experienced by the service and the moves that might be made to meet RTT targets There are three scenarios that were tested.

### 3.4.1 Baseline

The baseline scenario, where the model was fitted to reproduce supplied management information as closely as possible, this demonstrates the fitness of the model. That is, if it can't be used to replicate one snap shot in time then it can't be said to be a representation of the clinic in question.

### 3.4.2 Current growth

Baseline plus expected growth in referral volumes (25%). This applies the current growth in referrals over a number of years with no change to the resources available. That is, the workforce available to treat the patients. This scenario represents what will happen to the clinic's caseload and waiting time if they "Do Nothing."

### 3.4.3 Growth plus resource

A more optimistic scenario is that of expected growth with increased resource. The staff increase modelled was 50% in the first year of results collection across all specialties modelled.

## 3.5 Limitations of methodology

All methodology has its limitations and there are three that particularly apply to this approach: the frame problem; using theoretical models rather than actuals and having no estimation of error.

### 3.5.1 The frame problem

A model is essentially a representation of part of a system and can be as simplistic or complicated as is useful or practicable. At each stage of development the modeller has to ask "Is this new piece of information in or out of the model?" That is, they have to draw a frame around it and some things will be left out, simplified or estimated. This is a subjective process that is sometimes dictated to by lack of data, lack of knowledge about parts of the system to be modelled or a need to answer very detailed questions.

### 3.5.2 Using theoretical models

Limiting the modelling to that which is illustrative leaves the methodology open to challenge with respect to its relevance to particular clinics and potentially to its veracity as it has not been practically demonstrated. The purpose of theoretical modelling is to highlight issues and promote debate of possible solutions. The practical modelling may allow the offline testing of possible solutions, which is not available through the method used here.

### **3.5.3 No estimation of error**

Each scenario has been run four times in a process called “running a trial.” Although this process gives a feel for how stable the model is and the range of values that it might estimate it does not give a full sense of the error in the model. Error is a combination of the stability of the model, the impact of what has been simplified or omitted in the framing process, the assumptions that have been made and data it has been fitted to. In order to overcome these sources for error, we have designed gross scenarios. That is, the scenarios represent large changes that are easily observed rather than smaller changes whose impact may be swamped by or within the bounds of error.

## 4 London

### 4.1 Background on London clinic

London is the largest GIC in England, taking 55-60% of new referrals in 2014/15 that is around 95 per calendar month. The GIC has 6.9 WTE clinical staff comprising 3.9 WTE psychiatrists, 1.0 Speech and Language therapists, 1.6 WTE clinical psychologists and 0.4WTE endocrinologist. It is contracted on a block basis by London Regional Team.

### 4.2 Observations from visit

When I visited London, they were in the process of implementing a piloted scheme of streaming their new referrals and offering those who were more “ready” an information workshop so that they could make the best use of the waiting time (around a year). For example, if a patient needed to lose weight in order to be given hormone therapy or receive surgery then they could be made aware of this requirement at the workshop and then use their waiting time to prepare for treatment. The intention is to enable people to fast track through the process once they get to the front of the queue. It is estimated that 40% of patients will be treated in this way (green pathway). The remaining 60% are expected to need more time and support to make decisions regarding their pathway through the process (red and amber pathways). These groups of patients have access to psychological therapies, have a higher dropout rate and are less likely to proceed to surgery. This full triage of the queue coupled with streaming is unique to London.

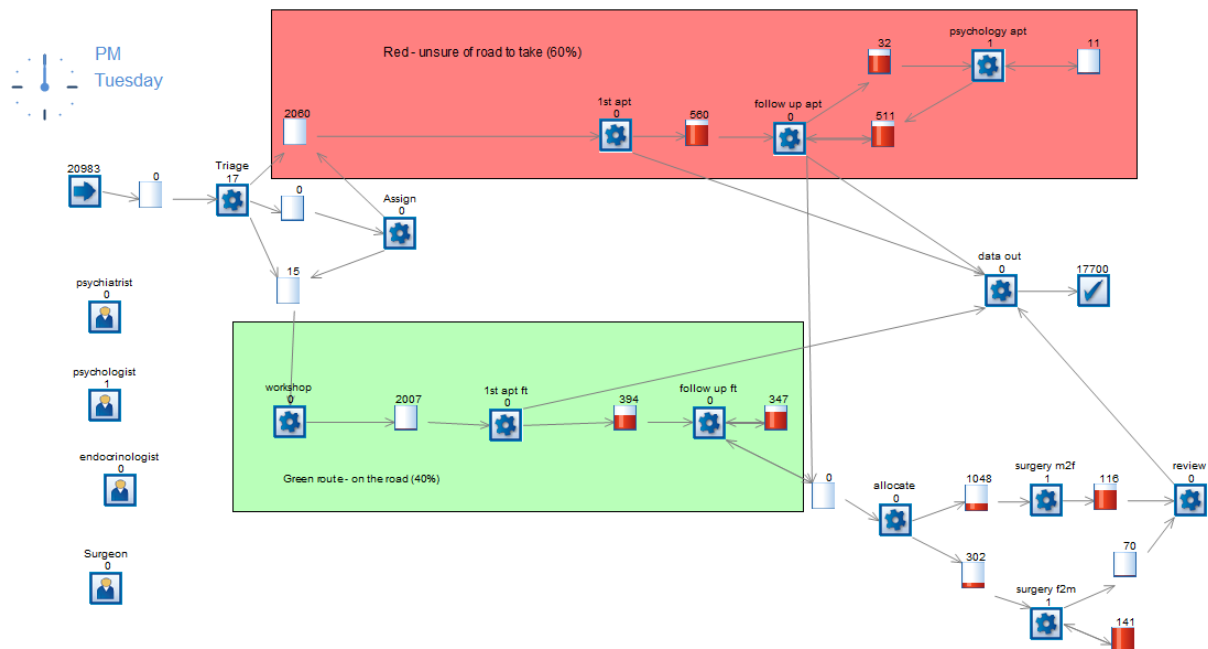


Figure 4.1: A schematic of the London Pathway drawn in Simul8

### 4.3 Observations

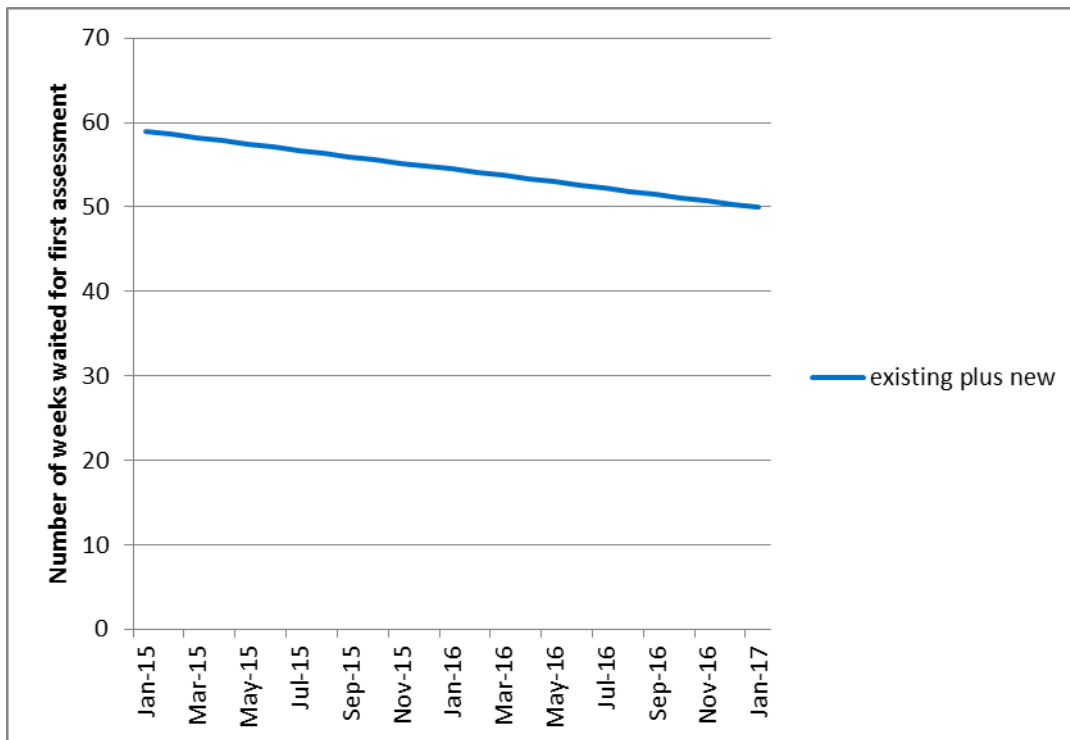
Figure 4.1 shows a schematic of the London patient pathway drawn in Simul8. It illustrates the full streaming of the queue but not the amber pathway. The London patient pathway was the most linear observed. That is, it has distinct phases of



assessment, treatment, referral for surgery and review and there is little overlap between the treatment and referral phases.

#### 4.4 Analysis of available data

Figure 4.2 shows an indicative projection of the RTT waiting times standard at the London clinic. The clinic receives around 87 new referrals a month and sees around 95 new patients a month. There are around 1296 people waiting for their first appointment. Combining these figures indicates that in the next two years the London clinic will shave 9 weeks off its current RTT time of 59 weeks.<sup>9</sup> However, more resource will be needed to bring the waiting time down to within the 18 week standard.



#### 4.5 Conclusions

London is the only clinic whose resource at the time of visit was resulting in a projected falling waiting time. However, they do not appear to be resourced to bring the waiting time down rapidly and it will be several years before they meet the 18 week standard without intervention.

<sup>9</sup> See foot note 1 for data source

## 5 Exeter

### 5.1 Background on Exeter

The Exeter clinic has a case load of around 750 patients and received around 500 new referrals in the previous year. This proportionately large number of referrals is recent. Referrals grew by 45% in 2014/15. It has been running since 1980's and operates an MDT model involving psychotherapists, GPs and other medics and an Occupational Therapist. Current waiting times (Jan 2015) from referral to first appointment are around 15 weeks and the assessment process takes a further 23 weeks to complete. The majority of the patients come from the South West (62%) and the remainder come from elsewhere (38%). The clinic also provides some services for Wales.

### 5.2 Observations from visit

The Exeter clinic, at the time of visit, has the most clinically intensive model of the six visited, in terms of patient contacts, but makes significant use of a wider MDT to deliver care. They also had the most advanced immediately available management information, which covered activities, waiting times and costs by various patient types.

### 5.3 Analysis of available data

Figure 5.1 shows a schematic of the Exeter patient pathway. It has an assessment phase, which is common to all patients and then, following a care plan agreed with the patient, a range of support, medical and surgical treatment is available.

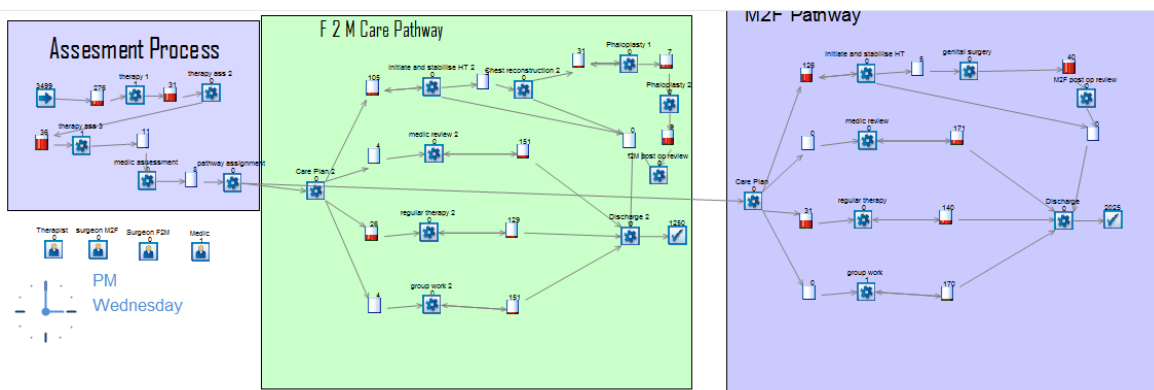
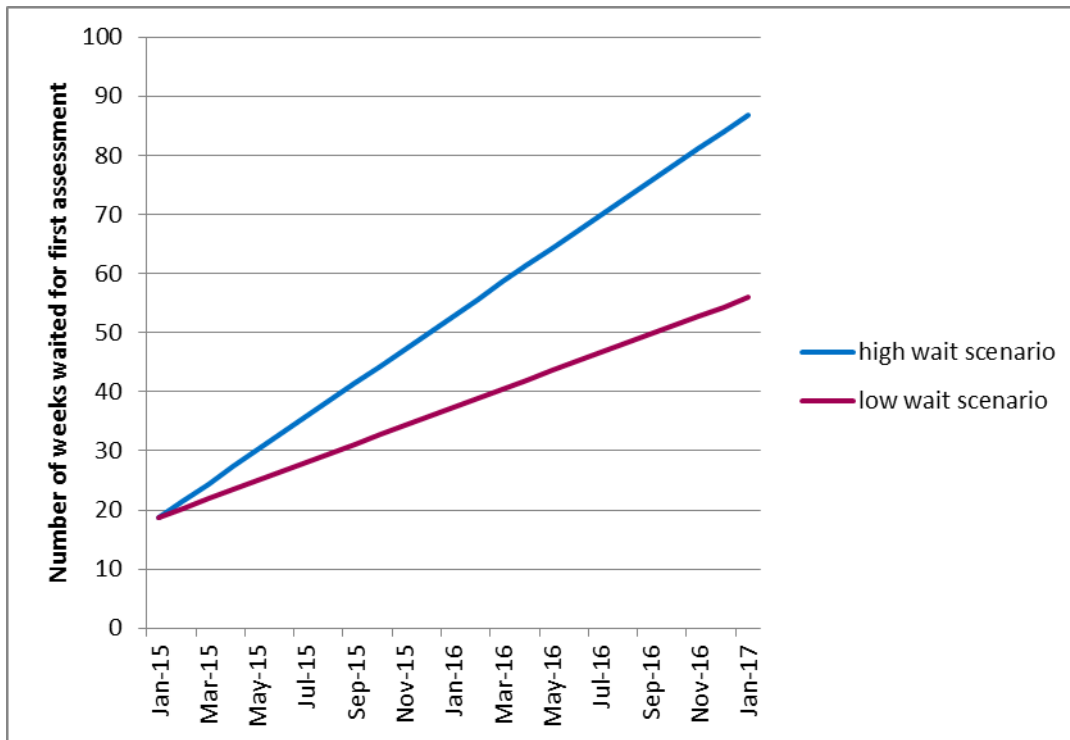


Figure 5.1 A schematic of the Exeter patient pathway drawn in Simul8

Figure 5.2 shows estimated performance against the 18 week RTT standard given data and resources available at the time of the visit. The clinic receives between 34 and 42 new referrals a month<sup>10</sup> At the time of the visit there were 109 patients waiting for their first appointment and the clinic was seeing around 25 new patients a month. The imbalance between new referrals and new patients seen leads to the projected growth in waiting times shown in Figure 5.2. Without additional resource waits at the Exeter clinic are likely to increase and this indicative analysis shows that it might slip from 18 weeks to 56 weeks over the next two years.

<sup>10</sup> See foot note 1 and from clinic data



#### 5.4 Suggestions concerning the patient pathway at Exeter

The Exeter pathway showed two vulnerabilities which are modelled in section 10

- 1) Any part of the pathway that requires two or more HCPs to be present at the same time can lead to scheduling strain or the build-up of backlogs. An example of this is the workshops, which require 2 therapists to be present. This observation could be made of most clinics.
- 2) Offering patients the same level of support throughout their treatment pathway leaves the clinic vulnerable to situations outside of their control. For example, surgical waits and waits for other treatments.

## 6 Summary report: Nottingham

### 6.1 Background on Nottingham

The Nottingham Clinic is the second largest in England having 15% of the national caseload. They treat patients aged 17+ and has been running since 1998.

### 6.2 Observations about the Nottingham Clinic

Nottingham had three innovations that I observed: training places, multi-skilled staff and socialisation.

Nottingham is currently the only clinic that offers a training place as part of the registrar rotation. The conversion rate from rotation to consultant is unclear.

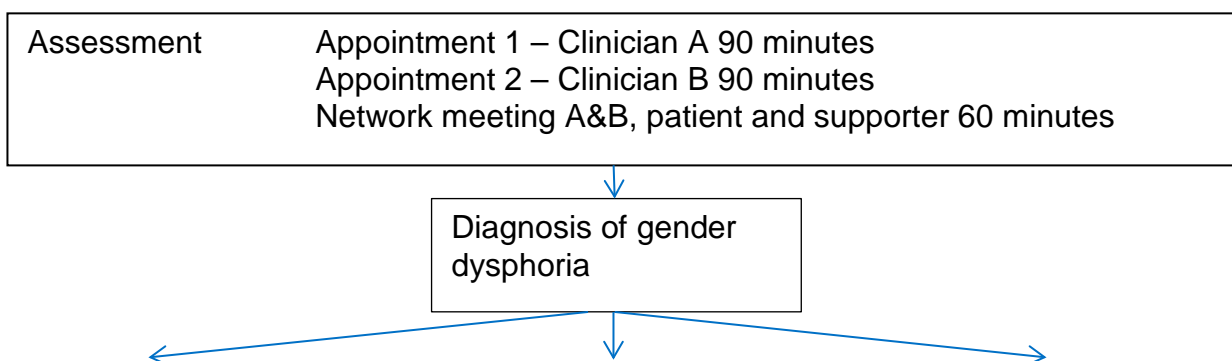
Nottingham also offers the innovation of multi-skilled staff. That is, their consultants are trained in psychiatry, can prescribe hormone treatments and have therapeutic skills. This means that the patient sees only one health care professional after their assessment is complete and clinic scheduling is easier as a result. It also offers a “one stop shop” approach for the patient and so they do not need to book multiple appointments to progress through their pathway. However, it is usually the case that the more specialist resources are the rarest. If this is the case, there may be a potential issue with rarity of resource in so far as finding people who are adequately skilled in all three disciplines and have an interest in working in the field of gender identity. However, it could also be the case that just those clinicians that are interested in this area are most likely to be multi-skilled so the sustainability of this workforce model would need to be researched further.

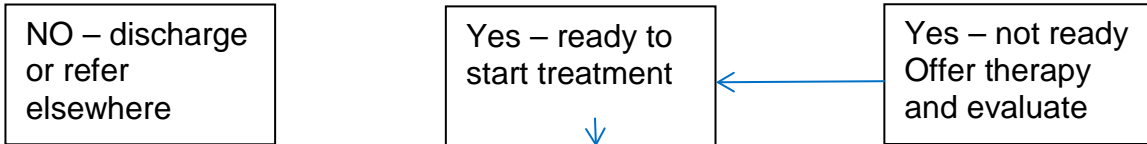
Finally, as part of the patient pathway, the clinic hosts a joint meeting between the patient, a friend or relative and the clinician that aims to socialise the transition that the patient is making. Ensuring the patient has the support that they will need and that there is a person or people within their circle that knows the treatment that they will go through over the coming months.

The Nottingham clinic has a history of contributing to and leading research and is in the process of constructing their patient information system to allow greater quantitative evidence to be accessible to this cause.

### 6.3 Data analysis

Figure 6.1 shows the care pathway for the Nottingham Clinic.



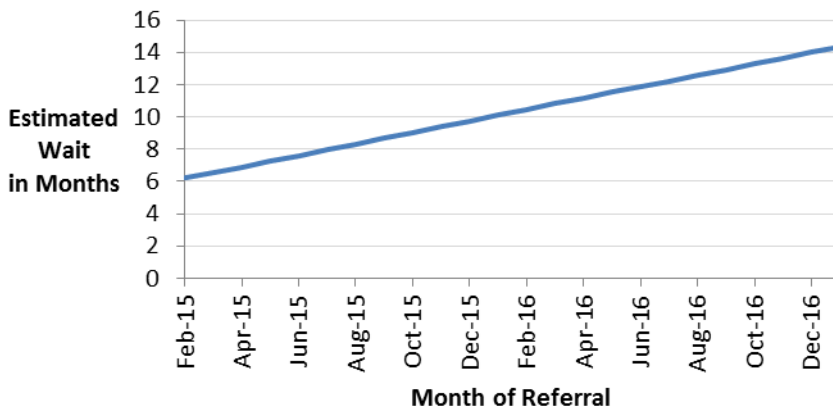


Start hormone treatment, live in chosen gender, change documentation  
 Meet every three months to monitor transition  
 After a minimum of a year: 2 expert opinions required for gender reconstruction surgery  
 6 months for chest reconstruction ( refer and follow up)  
 Referrals for endocrinology, voice coaching and individual psychotherapy available

The clinic currently has a caseload of around 1000 cases and received 850 new referrals in 2015. Their referrals have been growing by 55-60% per year over the last three years<sup>11</sup>.

The clinic has been, understandably, unable to respond to the rapidly rising demand, and as with everywhere else, the waiting list is growing and was at 8 months at the time of the visit. Figure 6.2 shows a projection of the waiting time for first appointment based and shows the waiting time rising to 15 -16 months by the end of 2016. This assumes that referrals stay at 2015 levels and the clinic’s capacity for new referrals is unchanged.

**Estimated Waiting Time for a First Appointment for a Referral - Nottingham**



*Figure 6.2: The projected waiting time growth to December 2016 for Nottingham*

The care pathway illustrated in Figure 6.1 does not describe ongoing support for patients waiting for surgery but in clarification the clinic states that this is available. The level of this support and whether this impacts on their capacity to take on new referrals, will be indicative of Nottingham’s resilience to other system capacity issues such as surgical waits.

<sup>11</sup> Nottingham Centre for Gender Dysphoria presentation pack 2015.

## **6.4 Suggestions**

It is not known what the effect of the breadth of specialism expressed in the consultant team has on their capacity to recruit others. As a unique resource model within the GIC community it could be reviewed as part of the workforce and training work of the clinical reference group, including its impact on patient care and outcomes.

## 7 Summary report: Newcastle

### 7.1 Background on Newcastle

Newcastle GIC holds 5% of the clinic population for England (c300 patients). However, it currently has the equivalent of two thirds of its clinic capacity on its waiting list (c. 200 patients.)<sup>12</sup> It has an outreach service to the local prison and have patients presenting with personality disorder as a co-morbidity. It operates under a block contract.

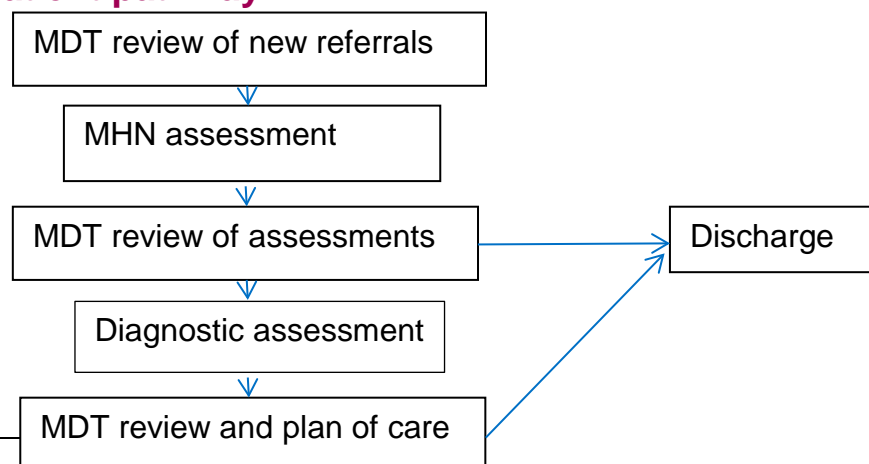
### 7.2 Observations about the Newcastle Clinic

The Newcastle Clinic has made extensive use of business modelling and forecasting in order to present the case for more resource and to flag up the persistent increase in demand. They have modelled a year on year increase in new referrals of 25%, which given recently published figures<sup>13</sup> is reasonably accurate. In each of the last two years they have experienced a 40% growth in new referrals. However, they have only been able to secure sporadic additional funding which has led to “tail gunning” the new referrals and this has caused ongoing capacity issues as the large cohort of new cases are assimilated into the service.

The pathway is a multi-HCP patient centred model. Newcastle have a range of therapy, psychology, medical follow up, MHN and speech and language therapy that any patient may access at any time as referred to by the MDT. The MDT act as a potential gateway at each stage of the pathway (referral, assessment, treatment and review) and provide exchange or information and multi-disciplinary input to complex cases.

At the referral stage, once all information is present, a MHN invites patients for a triage appointment where it is established as to whether they are ready to proceed to diagnostic assessment with the psychiatrist / medic. This triage stage can effectively weed out some of the referrals and lead to less medic time being needed for the new referrals than might otherwise have been the case. All the referral triage decisions are taken through to the MDT.

### 7.3 Schematic of patient pathway



<sup>12</sup> See footnote 1

<sup>13</sup> ibid

Classification: Official

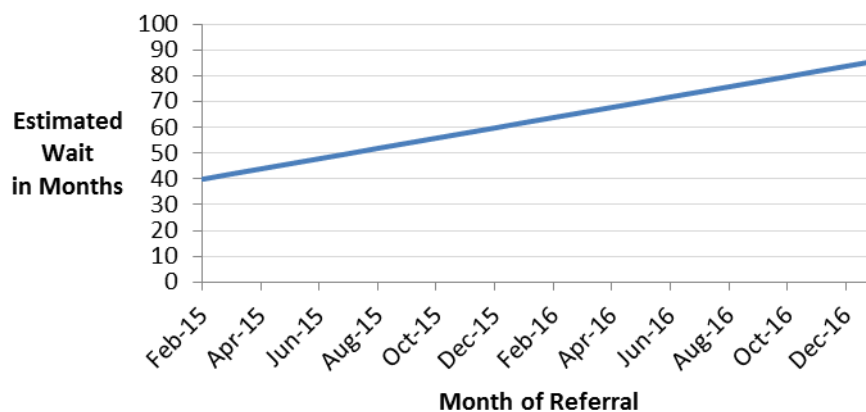


Patient pursues patient-centred care plan with c. 2.4 medical appointment per year  
Referrals for speech and language therapy and individual psychotherapy, psychology and MHN support are available  
Referrals for complex endocrinology, surgery and hair removal are made to external services

## 7.4 Data analysis

Newcastle has been estimated as seeing 5 new referrals per month and receiving closer to 15. This means that their waiting list is growing and will continue to grow rapidly. It is estimated that patients joining the list in February 2015 will be waiting 40 months and by the end of December 2016 this will more than double to slightly over 80 months. This does depend on the same level of demand continuing and no further resource being forthcoming, which may change given the contracting process that was ongoing at the time of my visit. This is illustrated in Figure 7.2

**Estimated Waiting Time for a First Appointment for a Referral - Newcastle**



*Figure 7.2: The projected waiting time growth to December 2016 for Newcastle*

## 7.5 Suggestions

It may be that Newcastle have been more explicit about their dependency on MDT meetings in decision making than other clinics, however, it does seem to be a



considerable commitment of resource especially for part-time staff for whom a fixed length fixed frequency meeting will be a disproportionate commitment of time. It may be beneficial to swap ideas with the Sheffield clinic on risk scoring patients so that not all patients are discussed at MDT each time but that some lower risk patients might be reviewed with just two HCPs. Obviously any change should be considered in balance with effects on patient care and quality and timeliness of clinical decision making.

## 8 Summary report: Sheffield

### 8.1 Background on Sheffield

Sheffield Porterbrook accounts for 4%<sup>14</sup> of the patient caseload in England (c.250 patients). They have around 100 patients on their waiting list.

### 8.2 Observations about the Sheffield Clinic

Sheffield have piloted and are starting to rollout a stratified or risk rated MDT approach where by only the most risky / complex patients are brought to the full MDT meeting and the less complex / risky are processed through MDT “lite” or two clinicians.

Sheffield have also invested heavily in evaluation/audit methodologies trialling new pathways and evaluating whether the changes represent an improvement to patient care and efficiency. The stratified MDT approach is an example of this process.

### 8.3 Schematic of patient pathway

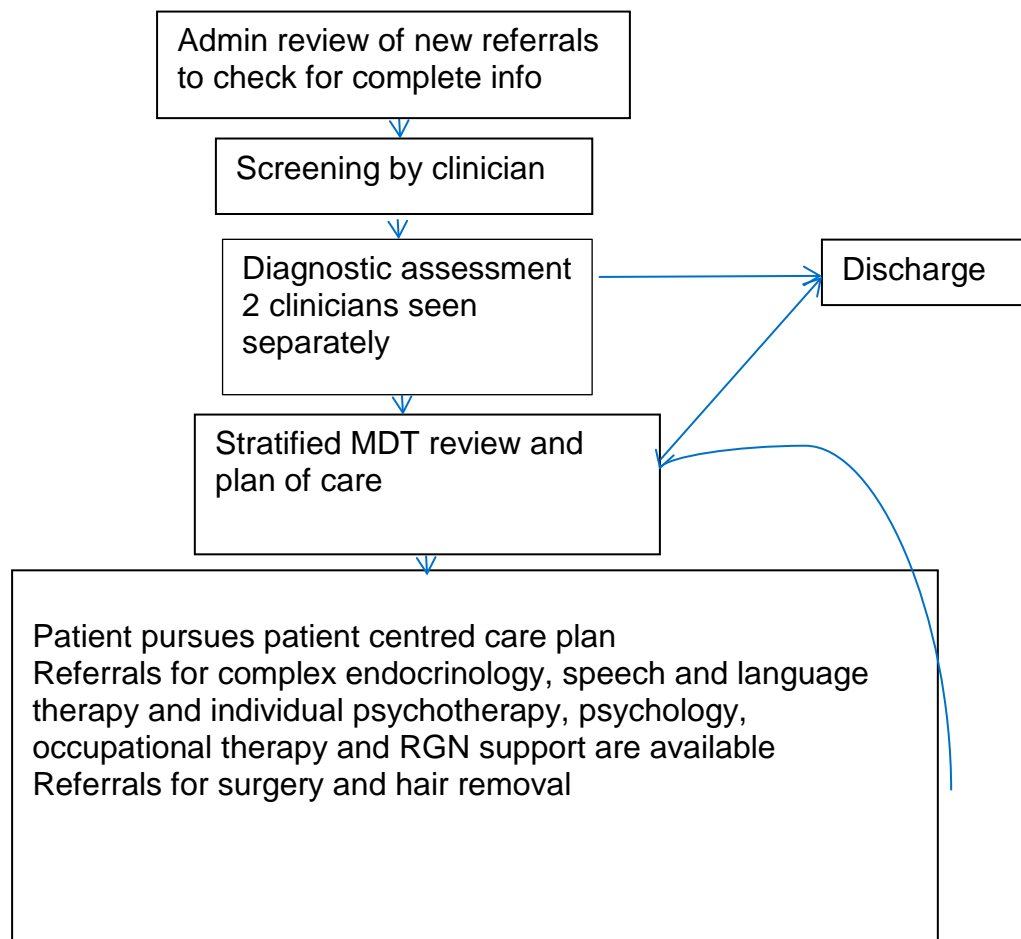
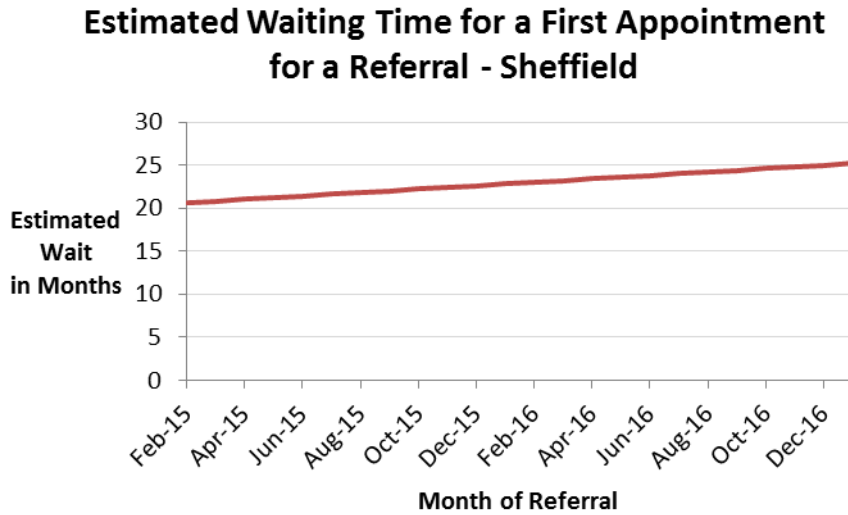


Figure 8.1 A schematic of the Sheffield pathway

<sup>14</sup> See footnote 1

## 8.4 Data analysis

Sheffield has an estimated waiting time of 20 months as of February 2015. However, this is projected to grow to 25 months by the end of 2016. Although this is not the worst or most lengthy waiting list in the country or the greatest growth it still indicates that the clinic in Sheffield is under-resourced for the demand that it is experiencing.



*Figure 8.2: The projected waiting time growth to December 2016 for Newcastle*

## 8.5 Suggestions

Since the clinical model operated by Sheffield is very close to that of Newcastle, it might be beneficial for Sheffield to explore the use of MHN in the screening and assessment phases and so free up some of their psychiatrist resource.

## 9 Summary report: Leeds

### 9.1 Background on Leeds

Leeds is one of the smaller GICs in England having around 5% of the patient caseload. Leeds follows the CR181 patient pathway explicitly. The majority of clinical activity is carried out by mental health nurses (MHN) with a part-time psychiatrist carrying out the clinician led parts of the pathway.

However, the clinical lead at the time of visiting, an MHN, is an active promoter of the service amongst their peers and so there is little difficulty in recruiting MHNs in Leeds, when finances or vacancies allow.

### 9.2 Observations about the Leeds Clinic

Leeds operates under a tight block contract and when the activity for the year is complete no further activity is done. For example, when the prescribed number of new referrals have been seen then no further new referrals will be seen in that year.

Given the scarcity of clinician resource at the Leeds clinic, offering second opinions on patients and filling in “individual funding requests” (IFRs) for additional surgery or hair removal have a disproportionate effect on available clinical time.

### 9.3 Analysis of available data

There are two sources of available data for Leeds. Their own data extract and the FOI data referenced earlier. From this data, the main analysis we can run is the waiting time for first appointment and how this may change over time.

#### 9.3.1 Waiting for a first appointment

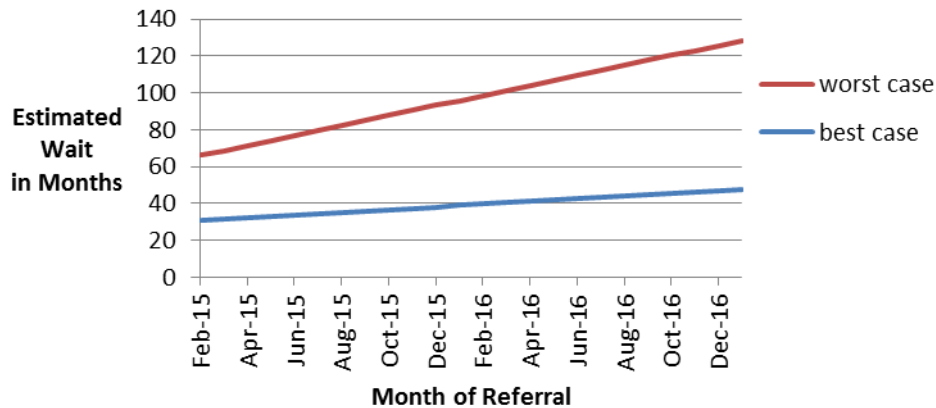
At present, it appears that Leeds receives approximately 26 new referrals each month. This is estimated from the 104 referrals received between October 2014 and the end of January 2015<sup>15</sup>. There were 26 first appointments in this time, giving an average of around 7 per month. From past data<sup>16</sup> on the number of patients who complete the assessment stage each month or who are discharged during this stage, it appears that as many as 15 patients per month may start the assessment stage. Using either of these estimates, there is clearly a mismatch between supply and demand; 26 patients join the waiting list for a first appointment each month but between 7 and 15 patients leave the waiting list. While this remains the case, the waiting list will increase each month by between 11 and 19 cases.

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<sup>15</sup> See footnote 1

<sup>16</sup> Data extract supplied by Leeds GIC

### Estimated Waiting Time for a First Appointment for a Referral



*Figure 9.2 The estimated waiting time in months for a referral joining the waiting list in each of the months from February 2015 to January 2016 based on data up to January 2015*

The current waiting list is large (462 at the end of January 2015), which indicates this mismatch has been an ongoing problem. Given the quality of the data, it is difficult to estimate what the past supply and demand have been or to establish any trend for these in future. The simplest assumption to make is that the system will continue to operate the mismatch described above. With this assumption we can estimate the likely wait for a patient being referred to the waiting list in February 2015. To do this, we further assume that new patients joining the waiting list will be treated after the 462 people who are ahead of them. Extrapolating the supply and demand in this way gives an expected wait of between 31 months (assuming fifteen leave the waiting list each month) and 66 months (assuming seven leave the waiting list each month) for new patients referred in February 2015. If we extend this method further, we find that this expected wait for a new patient joining the system continues to increase (by January 2017 the expected wait for a new referral could be anywhere between 48 months and 128 months).

### Conclusions and recommendations

Given the current lengthy waiting times at Leeds, it would be good if they were to make the patients in their queue aware so that the patients could then join queues elsewhere around the country. There is also a need to free up as much of their scarce psychiatrist resource as possible and, perhaps, resolving the specificity of the pathway so as to not require the use of the IFR process would be a step that would benefit this and other clinics.

## 10 Theoretical modelling of observations

This section describes three suites of models. The first two illustrate observations made during the visits and the third seeks to test out scenarios around achieving the 18 week RTT standard.

### 10.1 Observation 1

Appointments handled by more than one healthcare professional may put additional strain on the scheduling system and lead to longer waits for other appointments as a result.

A simple system was modelled with two resources type 1 and type 2 and three phases: assessment, review and therapy. Type 1 resource are deployed in assessment and review, type 2 resource are deployed in therapy and review. In the baseline scenario, shown in figure 10.1, two review appointments happen in sequence: one with type 1 resource, the other with type 2 resource. In the change scenario, shown in figure 10.2, the two review appointments are brought together to a joint appointment.

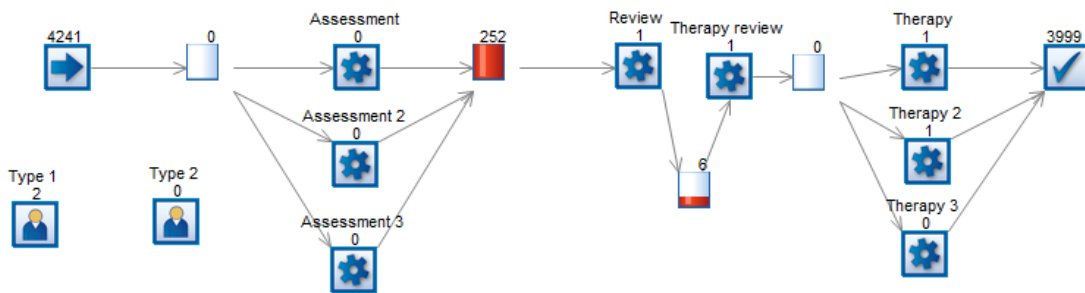


Figure 10.1 The Baseline diagram for observation 1

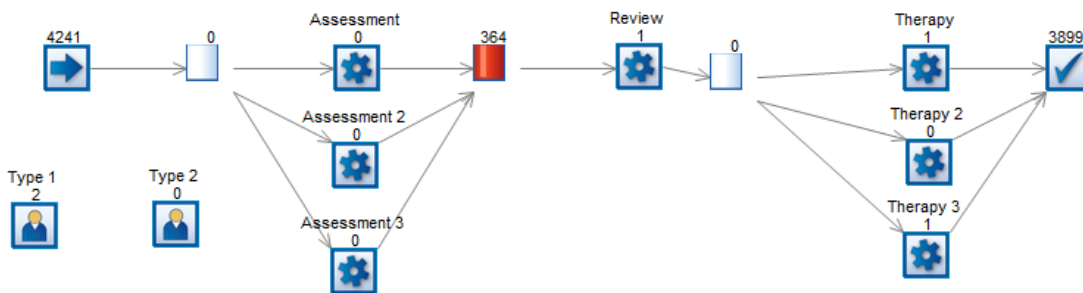


Figure 10.2 The Change diagram for observation 1

#### 10.1.1 Results

The average (mean) end to end patient journey increased by 46%, which is a result particular to this model, and the location of the relative delay is solely in an increase in the total queue time for the review appointments. This is illustrated in table 10.1

	Lower bound	Central Estimate	Upper bound	Utilisation type1	Utilisation type2	total q time in review

Baseline model	3623	3659	4695	84%	82%	4350
Change model	4413	5337	6261	83%	81%	6015
% difference	22%	46%	33%	-1%	-1%	38%
absolute difference	790	1678	1566	-0.01	-0.01	1665

Table 10.1 The results of models illustrating observation 1

### 10.1.2 Conclusion

This observation is not a recommendation to change all appointments to single HCP handled appointments as there are cited patient benefits and clinical reasoning behind their existence but that the added burden of the simultaneous availability of different HCPs should be factored into resource planning and evaluation of initiatives.

## 10.2 Observation 2

Some clinical pathways may be more susceptible to the effects of surgical delays than others.

A simple system was modelled where patients referred for surgery receive the same level of support as those starting treatment. The change model has patients referred for surgery receiving no support whilst waiting for surgery and then reviewed post-surgery. Both models had two surgical wait scenarios where time equals  $t$  and  $2t$ . In these models it is not the total number of appointments that is important but any observable change in the number of appointments when the delay is introduced.

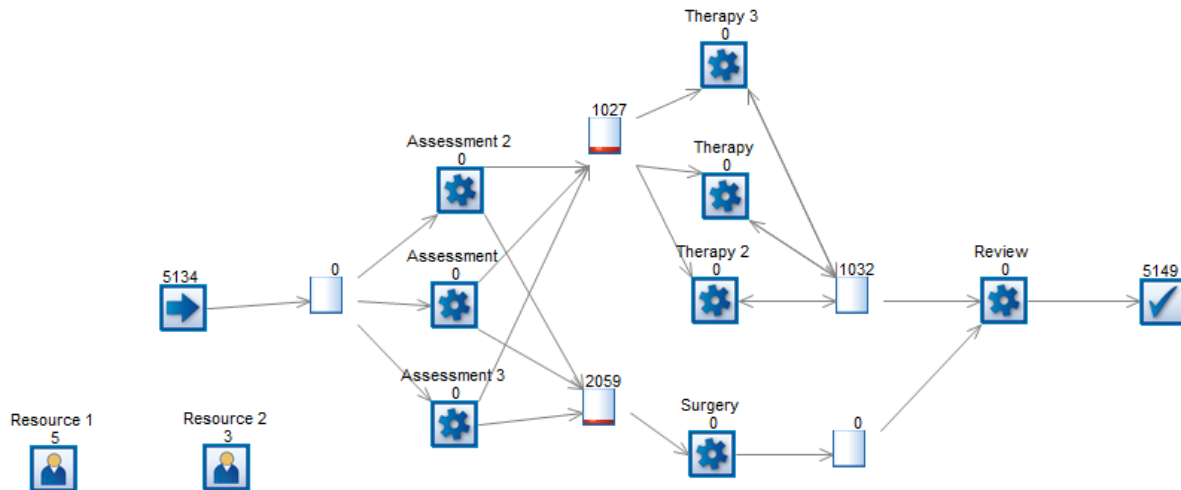


Figure 10.3 The Parallel Model for observation 2

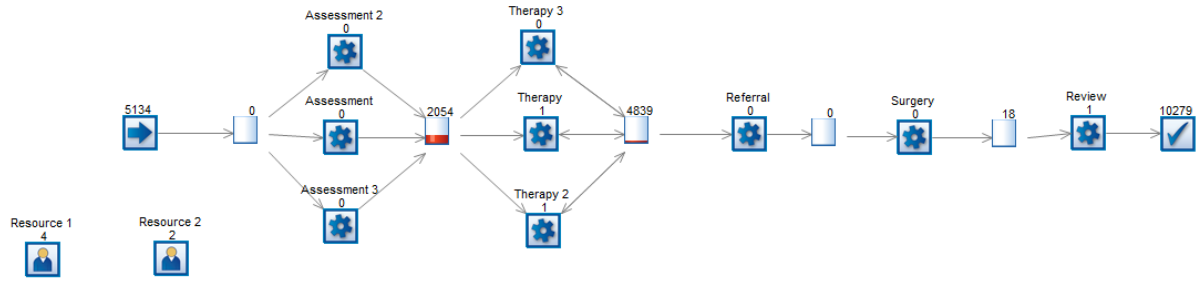


Figure 10.4 The Sequential Model for observation 2

### 10.2.1 Results

The key point of analysis was the additional appointment burden in the parallel model caused by the increase in surgical waits. It can be seen from table 10.2 that the parallel model delivers an additional 3 appointments following the increase in surgical waits whereas the sequential model shows no change.

	Surgical waits Time = t	Surgical waits Time = 2 t	% change
Parallel model	3	6	100%
Sequential model	3.5	3.5	0%

Table 10.2 The average number of appointments used before clearing surgery

### 10.2.2 Conclusion

The observation does not lead to a recommendation to discontinue support to patients waiting for surgery. Illustrating it with the model begins to demonstrate how vulnerable those clinics that provide continuous support are to an increase in surgical waits and leads to an encouragement to think about the system as a whole, understanding that the capacity to address increasing demand is linked to the waits for surgery. The level and frequency of continuous support varies between clinics and following the development of a consistent minimum dataset with outcomes data it may be possible to come to a collective decision concerning the level and frequency of support offered.

## 10.3 The impact of rising demand on RTT and the workforce requirement

In this section a theoretical clinic is modelled without the inclusion of the surgical pathway. The surgical pathway is omitted, not because it has no bearing on the achievement of RTT but because it is a complicating factor that has already been shown to have a demonstrable effect on clinic resources and the patient journey, depending on clinic design. The exclusion of the surgical pathway makes the end to end time short but the resource required to meet RTT should be unaffected.

The clinic is illustrated by a schematic diagram shown in Figure 10.5. The clinic has an assessment phase, a progressing or treatment phase and a review stage prior to



discharge. It takes account of many of the HCPs available at the different clinics and modes of appointment (1:1, 2:1 and workshop).

Three scenarios have been modelled: a baseline scenario where a steady state is achieved against which to bench mark the other two scenarios; a 25% growth scenario where the number of patients referred to the clinic grows at 25% per year for the life of the scenario; the growth plus 50% extra staffing to demonstrate the impact on the clinic of increasing staffing on waits generated by growth.

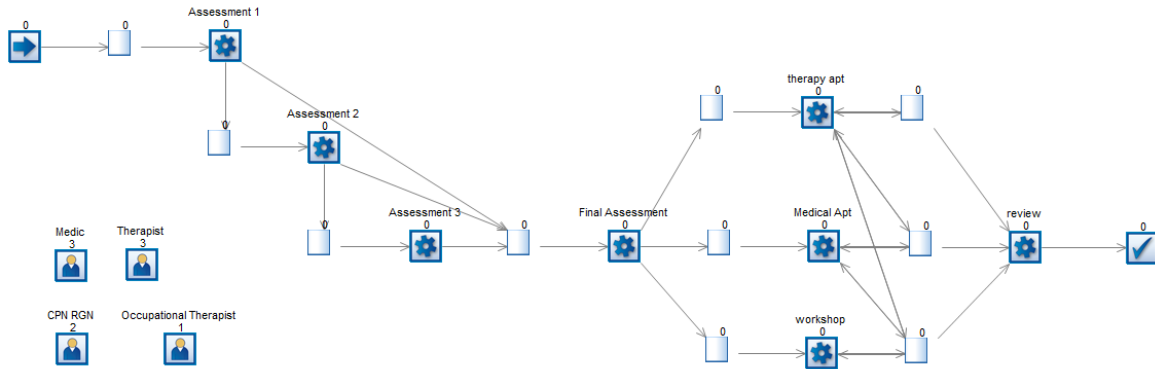


Figure 10.5 The schematic of the theoretical model drawn in Simul8

Figure 10.5 shows the schematic of the theoretical model and illustrates the different phases of the patient pathway. Table 10.3 lists the workstations in the model, where patient appointments occur, the number and type of staff required, the number of patients seen simultaneously, the duration of the appointment and where patients can go to and come from to that workstation.

Table 10.4 shows the staff resource available to the clinic by type, number and availability, which has been used to mimic part time working as well as non-patient facing time such as administration, MDTs and supervision.

Name of workstation	Resource required	Duration of apt	Patients seen	Total number of staff	Routes in	Routes out
Assessment 1	CPN RGN	90 minutes	1	1	New referrals	Assessment 2 70% Final assessment 30%
Assessment 2	CPN RGN	60 minutes	1	1	Assessment 1	Assessment 3 70% Final Assessment 30%
Assessment 3	CPN RGN	60 minutes	1	1	Assessment 2	Final Assessment
Final Assessment	Medic	60 minutes	1	1	Assessments 1-3	Therapy apt 10% Medic Apt 80% Workshop 10%
Therapy Apt	Therapist	60 minutes	1	1	Final	Medic Apt

					Assessment Medic Apt Workshop	Workshop Review
Medic Apt	Medic	30 minutes	1	1	Final Assessment Therapy Apt Workshop	Therapy Apt Workshop Review
Workshop	Occ. Therapist Therapist	90	2	12	Final Assessment Medic Apt Therapy Apt	Medic Apt Therapy Apt Review
Review	Medic Therapist	60	2	1	Medic Apt Therapy Apt Workshop	Discharge

Table 10.3 The workstation profile of the model

Staff type	Number of WTEs in model	% patient facing time
CPN RGN	2	35%
Medic	3	65%
Therapist	3	65%
Occupational Therapist	1	50%

Table 10.4 The resources available by staff type

### 10.3.1 Results

Table 10.5 shows the results of the modelling. The baseline model shows that for the resources modelled and the inter-arrival time of the patients the clinic can comfortably meet the 18 week target. However, placing the clinic under the strain that is indicative of that experienced currently by the GICs in the 25% growth scenario slips the RTT time out to 60.3 weeks and this is only brought back to 33 weeks by increasing the staff by 50%.

In order to bring it back down below 18 weeks it was necessary to double the number of workstations in the assessment phase of the model. This would be akin to adding four more rooms to a clinic. It was also necessary to add another nurse and OT as in both growth scenarios they were running at close to 100% utility which is not sustainable.

The staffing of the growth plus staff model is shown in table 10.6

Scenario	Utility % available time occupied				Time for RTT weeks	Mean number of appointments post assessment			End to End time weeks
	N	M	T	OT		T	M	W	
Baseline	98	54	64	99	8.4	1.5	1.7	1.1	45.0
25% growth	100	67	76	100	60.3	2.6	4.7	1.3	108.0
25% growth plus 50% staff	100	69	77	98	33.2				72.2

Table 10.5 Results from scenarios showing utility by staff type (N=nurse, M=medic, T=therapist, OT=Occ. Therapist), Time for RTT, Mean number of appointments post assessment (T=therapy, M=medical, W=workshop) and End to end time

Staff type	Number of WTEs in model	% patient facing time
CPN RGN	3	35%

Medic	5	50%
Therapist	5	50%
Occupational Therapist	2	37%

Table 10.6 The resources available by staff type for 25% growth plus 50% staff scenario

### 10.3.2 Conclusions

In order to meet the growing demand for GIC services it will be necessary to increase the staffing significantly, above and beyond that of succession planning. It may also be necessary to increase clinic infrastructure, that is consulting rooms available.

## 11 Comparative analysis and overall conclusions

This section gives comparisons between the sites. The first is the difference in their clinical staff, the second is in their clinical models and finally some comments as to whether the diversity of clinical models are within the bounds of CR181 which is based on WPATH7 [World Professional Association of Transgender Health Standards of Care version 7, Annex 2 ]

### 11.1 Clinic staffing

Table 11.1 summarises the different types and usages of staff in the GICs. A black square indicates that the clinic does not have this kind of staff, a question mark indicates uncertainty. Where possible I have indicated whole time equivalents (WTE). Gender specialists may be from many different clinical backgrounds, some specialising in mental health: psychologists, psychiatrists, counsellors or therapists, but they may also be GPs, endocrinologists,

Clinic	MHN	Therapist	Psychiatrist	Speech and Language	Occupational therapist
London		1:1 support for c. 1% of all referrals. Also runs support groups	3.9 WTE plus additional endocrinologist resource (0.4 WTE)	Consultant plus 1 WTE	
Exeter	Clinical team leader; works with complex clients	Used for initial assessment and ongoing support and group work	GP WSI clinical lead and 2.3 WTE other clinical resource	speech and Language Therapist	New resource 15/16
Newcastle	Used to monitor and support those waiting for surgery	Used for initial triage and support for specific issues	Dual qualified medic and psychiatrist 1 WTE	Speech and language therapist	
Leeds	Clinical lead, heavy use		Less than 1 WTE		OT
Sheffield	RGN rather than MHN	2 Psychotherapist – involved in assessment and ongoing support	2 * part time	Speech and language therapist	OT and access to image consultant
Nottingham		Psychologist available	2 WTE Hybrid resource – therapist and medic skills included		

*Table 11.1: The clinical staffing of the GICs*

### 11.2 Clinic models

Table 11.2 gives an overview of the clinical models operated by the GICs, summarising their key characteristics. For example, 4 clinics use MDTs in their care planning process, 1 does not and 1 is unknown. Most clinics offer a limited number of

appointments with a therapist but Exeter offered ongoing support as, in effect, Nottingham do. In contrast Leeds use MHN resource to offer ongoing psychological support. Only Exeter offers the same level of support for those waiting for surgery as to those at the beginning of the pathway.

Clinic	New referrals screened	Use of stratification	Use of MDT	Ongoing access to therapy / psychological support	Support continues through surgical waits
London	Triaged by clinician	Based on readiness to proceed	MDT for complex cases Separate general MDT	Limited	No
Exeter	Triaged by medic/therapist/clinical team leader	No	MDT is used for certain decisions in all patients (i.e. referral for GRS) and care planning for complex patients only.	Ongoing	Same level of support
Newcastle	Reviewed at MDT	No	Yes	Limited	Covered by MHN
Leeds	No	Not known	Not known	No - though significant use of MHNs	Not known
Sheffield	Yes – admin check and then clinical	Yes – risk/complexity based use of full MDT	Yes	Limited	Follow up only
Nottingham	Not known	Yes – based on readiness to proceed	No	Limited access to psychologist but all clinicians tri-trained	Not known

*Table 11.2: An overview of clinical the clinical models*

### 11.3 Comparison with WPATH7

WPATH7 states that they are flexible clinical guidelines, so one might expect that applying them would give rise to diverse patient pathways. There appear to be five roles or touch points for a GIC process recommended in WPATH7:

- Assess patient for gender dysphoria
- Provide information concerning options for expression and possible medical intervention
- Assess diagnose and discuss treatment options for co-existing mental health concerns
- Provision of psychological support, as appropriate to individual need
- If applicable assess, prepare and refer for hormone therapy
- If applicable assess prepare and refer for surgery
  - One referral for chest/breast surgery
  - Two referrals for genital surgery

In addition, WPATH7 states that mental health professionals<sup>17</sup> offer important support to clients throughout all phases and not just prior to an intervention. Thus, one might expect the availability of ongoing psychological support.

WPATH7 sets out minimum criteria for health professionals working in this area in the different roles but insufficient information was gathered to judge whether these criteria are met and it is also a role better suited to [clinical group name].

It is apparent from their pathways that all clinics assess patients for gender dysphoria, assess and prepare for hormone therapy and surgery (with the appropriate number of signatures). Clinics describe a process of assessment at the start of the pathway that may identify mental health and other co-morbidities, however, it wasn't clear from our discussions whether treatment options would arise from this process. The most variation around WPATH7 appears to be around the offer of psychological support and who does it. This varies from clinic to clinic as indicated in table 11.2 and may range from a limited number of sessions to tackle a specific concern to an ongoing therapeutic relationship that supports the patient through the end – to-end process.

## 11.4 Overall conclusions

From the process of visiting, discussing and describing each clinic, either as an overview or in detail in modelling, the following conclusions and recommendations are drawn.

- 1) That clinics share innovation and adopt each other's innovative practice where appropriate following appropriate evaluation

Nearly all clinics are introducing novel approaches to addressing the rising demand: from stratification and using more freely available resource to sift or screen patients

- 2) That the points in the pathways that currently require double handling be reviewed in the light of rising demand but kept in balance with the benefit to decision making and patient care

Many of the staff working in GICs do so part-time and it is a feature of part-time working that double handling situations such as workshops or MDTs have a disproportionate effect on their patient/ face to face time.

- 3) That growing the workforce should be a high priority and be planned to exceed succession planning

In reality this is still adding 1- 2 appropriately trained medical practitioners or clinical psychologists to every GIC in the near future plus replacing any losses through retirement or other exits. In addition, other HCPs such as MHNs and psychotherapists would also need to be increased to meet the rising demand.

- 4) That measures of success are developed for the service so that quality and patient outcomes and their impacts can be clearly demonstrated

There are currently no agreed measures of success or patient outcome measures. This makes determining good patient care and writing business cases very difficult

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<sup>17</sup> Note that WPATH7 is primarily written for an American audience; the term "mental health professional" does not refer exclusively to a psychiatrist or clinical psychologist. It is used to exclude graduates with a Bachelor's degree in psychology and no clinical training

since it only allows the rising demand argument to be made and not the impact argument. It is the latter argument that helps in decisions where funding is competitive with other services.

- 5) That the service plans for increasing complexity in their patient base (including co-morbidities and co-existing conditions)

Many clinics reported treating rising numbers of patients with personality disorders or Autistic Spectrum Disorders. These more complex patients may require additional clinical time or alternative means of support to navigate the process.

- 6) That the service agrees a core set of management information [Annex 3] and considers whether it should report to standard data collections such as HES Outpatients and Unify2 RTT.

Data was very hard to come by and was simply not provided for some clinics. To aid transparency and to be able to make swift comparisons and evaluate impacts, we would recommend that the service establishes a minimum dataset from which standard management information could be produced.

In addition to the formal recommendations we make the following suggestions:

- 1) One queue
  - We have no way of knowing whether multiple referrals have been made to different clinics for the same patient. A single queue would prevent this but also give a definitive count of those waiting
- 2) Same price, same contract
  - This would level the playing field between commissioners and providers. It may also produce more innovation and efficiencies. It should be adjusted for MFF to account for regional differences in expense and need
- 3) Estates and overheads
  - The quality and utility of estates varies between the six clinics visited. The organisational overheads paid to their sponsoring body may reflect this. It could be investigated whether it is cheaper (and so free monies to expand the service) to host the service in secondary care than in MHTs
- 4) Specify without recourse
  - Patients and staff spend a great deal of time following procedures for bespoke decisions (e.g. breast augmentation, further hair removal etc.). These processes are designed for very exceptional circumstances. The volume of patients coming through should now take them out of this process and local determination. Specifying more clearly what is and what is not included and leaving no appeal process would save clinical time and give patients clearer expectations from the start

## 11.5 Thanks

Finally, our gratitude must go to those that gave up clinical time in a hard pressed service to participate in this exercise. It is hoped that as this work passes to the

Specialised Commissioning Analytical Team that a foundation has been set from which future business cases and service developments can be built.



## **12 Annex 1: Reference for methodology**

The core text for the methodologies applied in this research is  
“Tools for Thinking” Pidd, M. Wiley 2009

Other texts include:

“Soft Systems Methodology in Action”, Checkland, P. Wiley 1999

“Discrete Even Simulation”, Brailsford, S. Wiley 2014

## **13 Annex 2: WPATH v7**

[http://www.wpath.org/site\\_page.cfm?pk\\_association\\_webpage\\_menu=1351&pk\\_association\\_webpage=3926](http://www.wpath.org/site_page.cfm?pk_association_webpage_menu=1351&pk_association_webpage=3926)

accessed 17/7/2015

## 14 Annex 3: Suggestions for a minimum dataset for GIC services

The table below is illustrative of a standard minimum dataset for the service. Note that submission to either HES Outpatients or a Community Mental Health collection and the RTT Unify2 return will have additional requirements. Also that advice should be sought from the HSCIC concerning the process of defining and submitting data, particularly in the area of complying with or amending the NHS data dictionary to take account of new data items to be collected.

### 14.1 The 18-Week RTT Standard

As stated in the RTT (Referral to Treatment) rules suite, patients “have the right to access certain services commissioned by NHS bodies within maximum waiting times, or for the NHS to take all reasonable steps to offer a range of suitable alternative providers if this is not possible”. The current RTT standard by which providers are assessed is that at least 92% of incomplete pathways (i.e. the waiting list) must have been waiting less than 18 weeks (the remaining 8% representing an operational tolerance allowance).

For the gender identity service, it appears that there are two separate RTT pathways within the overall care pathway.

Pathway 1:

- Clock starts when a patient is referred to a Gender Identity Clinic.
- Clock stops when: a patient starts initial care plan, or is discharged. The clock also stops if a patient begins a period of active monitoring – this is not a clock pause event as stated in the January UK Trans Info document.

Pathway 2:

- Clock starts when a patient is referred for gender reassignment surgery.
- Clock stops when a patient is admitted for surgery, or is discharged.

For providers submitting data to the Unify2 RTT collection, data is collected with the patients grouped into weekly “time-bands” according to how long they have waited (e.g. 0-1 weeks, 1-2 weeks etc.). This data is collected both for patients whose pathways have been completed and for patients whose pathways remain incomplete (i.e. the waiting list), though the standard only applies to incomplete pathways.

The data provided does not split easily into these two RTT pathways; however, the wait times are so large that it seems clear that the average patient’s waits for these RTT pathways would substantially exceed 18 weeks. For example, the average wait for a first appointment for the period

Oct-14 to Jan-15 was quoted in the UK Trans waiting times report as 69 weeks, and the average wait in 2014 for surgery following a second opinion appears to be more than 40 weeks. Another issue with assessing the RTT performance of Leeds Gender Identity Service is that the data provided shows the average wait experienced by patients who have completed various pathway stages; it does not provide any information about the waiting times being experienced by patients still on the waiting

list. For providers submitting data to the Unify2 RTT collection, data is collected with the patients grouped into weekly “time-bands” according to how long they have waited (e.g. 0-1 weeks, 1-2 weeks etc.). This data is collected both for patients whose pathways have been completed and for patients whose pathways remain incomplete (i.e. the waiting list), though the standard only applies to incomplete pathways.

Section	Data Item	Use
Patient Information	Age at referral	Basic stat about who is using the service
	Source of referral	Able to track where referrals are coming from eg GP, prison service, other NHS, Tavistock etc
	Co-morbidities present	Suggest yes/no field to estimate complexity of caseload
	ICD10 code(s)	Possible way of quickly listing co-morbidities
	Age of awareness	A way of tracking whether growth is linked to people seeking help earlier (or finally)
	Other services accessed prior to referral	Useful for citing value added in providing definitive treatment
	Birth gender	Basic stat about who is using the service
Care Pathway	Date of referral	Essential in tracking 18 week pathway
	Date of first appointment	Essential in tracking 18 week pathway
	Date of care plan	Essential in tracking 18 week pathway
	Date care plan initiated	Essential in tracking 18 week pathway
	Initial pathway selected	Signals initial intent of patient
	Final pathway followed	Difference between final pathway and initial pathway may indicate part of value added
	Non-genital surgery referral date	Patient tracking fields and can help indicate how many people are waiting for this service
	Epilation referral date	Patient tracking fields and can help indicate how many people are waiting for this service
	Genital surgery referral date	Patient tracking fields and can help indicate how many people are waiting for this service
	Non-genital surgery completion date	Patient tracking fields and can help indicate how many people are waiting for this service

	Epilation completion date	Patient tracking fields and can help indicate how many people are waiting for this service
	Genital surgery completion date	Patient tracking fields and can help indicate how many people are waiting for this service
	Number of medical appointments in year n	Counting patient contacts will enable business modelling re capacity and utilisation to take place
	Number of therapeutic appointments in year n	Counting patient contacts will enable business modelling re capacity and utilisation to take place
	Number of workshop appointments in year n	Counting patient contacts will enable business modelling re capacity and utilisation to take place
	Number of other HCP appointments in year n	Counting patient contacts will enable business modelling re capacity and utilisation to take place
	Date of discharge	Will give duration of pathway
	Reason for discharge	This will track the number of people completing or being discharged for DNA etc.
Patient Outcomes	BMI at referral	Patient's may present with a BMI > 25 but have to lose weight to prepare for surgery or take hormones
	BMI on discharge	Patient's may present with a BMI > 25 but have to lose weight to prepare for surgery or take hormones
	Employment status on referral	These two fields demonstrate whether there has been an effect on the patient's capacity to engage with the labour market
	Employment status on discharge	These two fields demonstrate whether there has been an effect on the patient's capacity to engage with the labour market
	Dysphoria score? At referral	I don't know if such a thing exists but there may be some measure that would allow clinics to demonstrate that they had helped
	Dysphoria score? At discharge	I don't know if such a thing exists but there may be some measure that would allow clinics to demonstrate that they had helped
	Depression/ Anxiety score at	Some quantitative assessment of mental well-being. Difference

	referral	between start and end indicates impact of treatment
	Depression/ Anxiety score at discharge	Some quantitative assessment of mental well-being. Difference between start and end indicates impact of treatment
Geographic information	GP Surgery	Essential activity tracking information
	CCG	Essential activity tracking information
	Region	Essential activity tracking information
	Clinic accessed	Essential activity tracking information