Development of metrics to measure the impact of Tommy’s work

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Preface

RAND Europe has been commissioned by Tommy’s to support them as they develop a new strategy for their charitable spending over the next four years, both with their strategic thinking and the development of metrics to measure the impact of their work. This report provides findings of the evidence gathered and analysed by RAND Europe.

This report should be of interest to senior staff at Tommy’s, members of staff at the clinics and research centres funded by Tommy’s, clinicians and academics engaged in the research themes supported by Tommy’s, and various stakeholders associated and engaged with Tommy’s cause.

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In this report, we present a set of metrics to help work out what Tommy’s should measure and how Tommy’s should report impact. These metrics cover four different elements of Tommy’s strategy: the research centres, the implementation centre, the pregnancy information service, and the clinics. The aim is to work out how each contributes to Tommy’s desired outcomes, namely the reduction of stillbirth, preterm birth and miscarriage.

We carried out the research using a mixed-methods approach involving a workshop with Tommy’s, a focused review of existing frameworks and Tommy’s strategy documentation, interviews with key stakeholders engaged with Tommy’s mission, and an internal workshop.

Although the study is primarily intended to inform Tommy’s approach to measuring the impact of their work and their strategy on charitable spending, it is also likely to be of relevance to Tommy’s funders, clinicians, academics, other charities, and any stakeholder who shares Tommy’s mission to ensure that fewer babies die during pregnancy and birth.
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Abbreviations

A&E  Accident and Emergency
FSID  Foundation for the Study of Infant Deaths
GP  General Practitioner
ISD  Information Services Division
KCL  King's College London
MSDS  Maternity Services Data Set
NHS  National Health Service
NICE  The National Institute for Health and Care Excellence
NMPA  National Maternity and Perinatal Audit
NRS  National Records of Scotland
ONS  Office of National Statistics
PHE  Public Health England
PREMs  Patient Reported Experience Measures
PROMs  Patient Reported Outcome Measures
QALYs  Quality Adjusted Life Years
REF  Research Excellence Framework
SANDS  Stillbirth and Neonatal Death Society
SHiP  Spontaneous Haemoperitoneum in Pregnancy
SSBIDS  Scottish Stillbirth and Infant Death Survey
THIS Institute  The Health Improvement Studies Institute
UK  United Kingdom
UKOSS  UK-wide Obstetric Surveillance Survey
The authors would like to thank Tommy’s, who commissioned this study. In particular, Jane Brewin of Tommy’s provided support and helpful advice throughout the study. We would also like to thank the participants in the stakeholder consultations for their valuable time and inputs to this study. In addition, we thank Dr Asha Carpenter and Jack Pollard (RAND Europe) for their research support. Finally, we very much appreciate the incisive and timely feedback provided by our RAND Europe quality assurance reviewers, Dr Molly Morgan Jones and Dr Sarah Ball.
1. Background and context

1.1. Introduction

In this chapter, we discuss Tommy’s mission and the previous RAND Europe work which formed the basis of its current impact indicators. We discuss the need to update these indicators and establish this study’s objectives, and we set out the approach used in this study.

1.2. About Tommy’s

Tommy’s was established in the early 1990s with the aim of making pregnancy safer and reducing the number of babies who die during pregnancy or at birth. Tommy’s mission statement is as set out in the box below.

Box 1 Tommy’s mission

More than one in four families in the UK will lose a baby during pregnancy or birth. At Tommy’s, we believe that every pregnancy deserves a happy ending. Our mission is to halve the number of babies that die during pregnancy or birth by 2030.1

1.3. Different components of Tommy’s work

The diagram below depicts the different components of Tommy’s work towards its overarching aims. Tommy’s primarily seeks to achieve these aims through the four research centres that it funds in the UK at St Thomas’ Hospital (King’s College London (KCL)), St Mary’s Hospital (University of Manchester), Edinburgh Royal Infirmary (University of Edinburgh), and the National Centre for Miscarriage Research which is located across three universities and hospitals. At each of these centres, Tommy’s provide a mix of infrastructure funding and fellowship/salary funding for core staff. This enables significant further funding from other sources to be leveraged through these centres of excellence. Also associated with each centre is a clinic where treatment is offered as part of wider National Health Service (NHS) provision, which may be informed by the research in the associated centre. These clinics also serve as source of recruitment for studies conducted through the centres.

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1 Tommy’s (2004).
In addition to research support, a significant element of Tommy’s work is the pregnancy information service. This includes information provision hosted on their website, a midwife-led expert helpline, and utilisation of social media to engage parents. Tommy’s also works with a range of organisations to distribute information, as well as producing some information on behalf of NHS England. This stream of work interacts significantly with the research stream, providing a route to disseminate findings, helping to establish research priorities, and also generating a community of engaged and motivated supporters who help drive forward the interests of the charity and its mission.

Tommy’s current strategy, set in 2014, has coincided with a 38 per cent increase in voluntary donations (in 2016), raising vital funds to support the addition of a miscarriage-focused research centre, and an increase in the scale and impact of their pregnancy information service.\textsuperscript{2,3,4} More recently, there have been even greater increases in the research funding budget, from £1.7m to an estimated £2.7m in 2018/19. Another important development over recent years has been an increasing shift from Tommy’s early focus on basic science research to the development of a wider research portfolio spanning basic research as well as clinical and health services research.

With an increased budget, Tommy’s is looking to expand its operations to include the funding of large fellowships. The goal of this initiative is to grow capacity in the field and to support implementation research to promote the systematic uptake of research findings and other evidence-based practices into routine practice in the NHS and at home.

\textsuperscript{2} Charity Commission (2017).
\textsuperscript{3} Tommy’s (2014).
\textsuperscript{4} Tommy’s (2016).
1.4. Tommy’s approach to measuring impact

RAND Europe previously helped to develop a succinct and balanced set of performance indicators to measure Tommy's own activities, the activities Tommy's funds, and the impacts these activities have on parents and their babies.

This work was driven by the growing need to demonstrate impact to funders and the need to continue to support learning within the organisation about what works best and under what circumstances. The framework gave Tommy’s the capability to provide compelling evidence of its performance, which allowed Tommy’s to both demonstrate its impact and learn lessons for future improvement.

RAND Europe’s previous work with Tommy’s aimed to advance their performance reporting toward a more consistent method for reporting output and impact of the funded research across their four research streams. These metrics are collected yearly and contribute to Tommy’s annual performance evaluation.

The annual reports are focused around the following three areas of impact, based on stakeholders’ interest:

- Local clinical impact
- National clinical impact
- Significant research findings.

In addition to research support, RAND Europe’s previous work also considered the pregnancy information service, which is a significant element of Tommy’s work. The impact of this stream of work is intended to be measured through:

- Reach (e.g. unique visitors to the website)
- Change in behaviour as a result of information provision.

As mentioned above, this stream of work provides a route to disseminate findings and helps to establish research priorities. It also generates a community of engaged and motivated supporters who are crucial to furthering the interests of the charity and its mission.

Tommy’s is looking to expand its operations to grow capacity in the field through funding of large fellowships. It also aims to support implementation research to promote the systematic uptake of research findings and other evidence-based practices into routine practice. The current strategy has been extremely effective in maximising the impact of a small charity and leveraging the funding and community support available to Tommy’s. As Tommy’s moves from a small to a medium-sized charitable research funder and diversifies its research funding model, a new approach is needed to engage with beneficiaries, funders and the research community to demonstrate the impact of Tommy’s funded research.

1.5. Study objectives

RAND Europe was commissioned by Tommy’s to support them as they develop a new strategy for their charitable spending over the next four years. This will be to support their strategic thinking and the development of metrics to measure the impact of their work. They asked that this be a collaborative process involving representatives of all their stakeholders to decide how Tommy’s measures the impact of its investment in the future. The aims of this study were to:
• Review and develop appropriate metrics to measure the impact of Tommy’s work based on international best practice;

• Consult key stakeholders to ensure metrics and measures are feasible, acceptable, and represent the nature of Tommy’s contribution.

1.6. Study design and approach

The work consisted of four tasks as set out on the Figure 1.2 below.

Figure 1.2 Study design and approach

- Task 1: Developing a draft logic model
- Task 2: Prioritisation and mapping of indicators
- Task 3: Stakeholder consultation and data review
- Task 4: Reporting and dissemination

Source: RAND Europe

Each of these tasks is explained in more detail below.
1.6.1. **Task 1: Developing a draft logic model**

**Description**
The aim of this task was to understand Tommy’s current and planned activities and their intended contributions to the wider mission of the organisation, in order to enable Tommy’s to create an overview logic model framework representing their work as an underpinning for the generation of relevant measures and metrics. The work consisted of a review of Tommy’s strategy documentation, a workshop and discussion with Tommy’s leadership, and a review of existing frameworks in the literature for the measurement of research impact.

**Intended output**
Logic model depiction of Tommy’s research centres, implementation centre, information service and clinics across input, process, output, outcomes and impact.

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1.6.2. **Task 2: Prioritisation and mapping of indicators**

**Description**
The aim of this task was to identify and prioritise relevant metrics for the measurement of the work Tommy’s supports across streams as a starting point for wider feasibility and acceptability testing in Task 3. This work consisted of developing a longlist of metrics from the existing literature, rating these based on their relevance to Tommy’s and the effort required to collect them, prioritising them on that basis, and mapping them onto the framework developed in Task 1.

**Intended output**
A set of indicators to measure impact for Tommy’s research centres, implementation centre, information service and clinics across input, process, output, and outcomes.

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1.6.3. **Task 3: Stakeholder consultation and data review**

**Description**
This task was intended to refine and, where appropriate, narrow down the set of indicators under consideration based on practical considerations and wider perspectives. The work consisted of 11 interviews with representatives covering each of the research centres, the information service, members of Tommy’s board of trustees, and other expert informants in the field such academics not affiliated with Tommy’s research centres and healthcare industry experts. This task also included a review of relevant datasets and sources, and an internal workshop to draw together and implement the evidence and feedback.

**Intended output**
Revised and updated set of impact indicators.

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1.6.4. **Task 4: Reporting and dissemination**

**Description**
The aim of this task was to report and share findings of the work in a clear and accessible format.

**Intended output**
Finalised set of indicators and a detailed slide set/report.

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In the next chapter, we discuss the findings of the study, including the logic model and a set of metrics to measure the impact of Tommy’s work.
2. Results: Logic model and indicators

2.1. Introduction

In this chapter we discuss the overall logic and the metrics to measure the impact of Tommy’s research centres, implementation centre, information service and clinics. To begin with, we developed an initial logic model to represent the activities of the organisation and their intended contributions based on our initial workshop with Tommy’s and a review of their strategy documentation. Through Task 2, we identified existing metrics and measures used internationally, which we prioritised and mapped onto the framework. Both the logic model and framework were then tested and refined through consultation with a wide range of stakeholders involved in Tommy’s work. The following sections set out:

- Key findings/outcomes from each stage of this process;
- The final logic model overall, and indicators for each element of the logic model (the discussion for each section describes key inputs from stakeholders which shaped the development of the framework and indicators);
- Challenges and limitations in the measurement of impact;
- A lay version of the framework which could be refined and used for wider communication purposes.

More information on logic models, our longlist of indicators from the literature, and a list of individuals consulted in the consultation process are included in the annexes to this report.

2.2. Task 1: Developing a draft logic model

A key initial step was to consult in detail with Tommy’s leadership to establish the aims of the charity and the ways in which the different areas of work they support, and plan to support in the future, contribute to those aims. A clear message was that the overall aim common to all of Tommy’s work is the reduction in levels of stillbirth, miscarriage and preterm birth, and this should be the ultimate impact of all elements of their work. However, the ways in which the different streams contribute differ and this was explored in detail. It was also emphasised that the final framework and metrics should speak to donors and families as well as experts and researchers, and that a lay presentation of the framework might help support this.

Building on the inputs provided by Tommy’s through our discussions and a review of the strategy documentation provided, we reviewed existing frameworks in biomedical and health impact measurement to identify options appropriate in this context. Two key sources informed this review. Firstly, a recent
comprehensive review of health research evaluation frameworks,\(^5\) which sets out in detail existing practice in the sector. Where relevant, we also drew upon the publications referenced in that review. In addition, we drew upon RAND Europe’s existing work developing frameworks for a range of national and international funders. In particular, to inform the elements focusing on the planned implementation centre, we drew upon recent work conducted for The Health Improvement Studies (THIS) Institute developing a framework and metrics to measure the impact of their work. The longlist of metrics based on these sources is identified in Annex C (Table C.1).

We then produced a draft framework which was refined in discussion with Tommy’s to produce an initial draft ‘straw man’ framework which was used to identify metrics and for consultation. Key changes made to the framework and metrics through the consultation process are set out in the following sections. However, there are challenges inherent to measuring the metrics identified which can obscure the true trends. These challenges and possible ways in which the proposed logic model could mitigate them are discussed in Annex B.

### 2.3. Task 2: Prioritisation and mapping of indicators

Task 2 consisted of the development and prioritisation of a longlist of potential indicators to measure the different strands of Tommy’s work. We generated a longlist by reviewing and extracting metrics used or proposed elsewhere. A key source for this was previous work by RAND Europe developing a list of 100 metrics for the evaluation of biomedical and health research.\(^6\) This was supplemented by our work for THIS Institute, the abovementioned review of evaluation frameworks and the papers referenced within it,\(^7\) and our previous work in mapping the range of benefits and measures used to characterise the outcomes of biomedical and health research.\(^8\) To this, we also added input from Tommy’s on existing measures and metrics compiled for both research centres and the information service. This generated a longlist of metrics which may be of relevant for the measurement and evaluation of Tommy’s work.

The longlist was then reviewed and rated by three separate experts within RAND Europe in terms of whether each metric is easy to collect, and the extent to which it aligns with Tommy’s goals, mission and strategy. This is illustrated in Figure 2.2. Metrics which are central and easy to collect are prioritised, whereas those which are less relevant and difficult to collect are discarded. However, there is a need to consider the overall balance of measures used and the extent to which they span the range of activities of the different streams of Tommy’s work. With this in mind, the metrics were also mapped onto the framework, starting with the priority metrics and then including other metrics where required to meet the needs of the framework. Where gaps were identified, literature was reviewed again and metrics were identified and/or adapted as required to ensure good coverage across Tommy’s proposed portfolio.

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\(^5\) Raftery et al. (2016).
\(^6\) Guthrie et al. (2016).
\(^7\) Raftery et al. (2016).
\(^8\) Pollitt et al. (2016).
2.4. Task 3: Stakeholder consultation and data review

The draft framework and metrics produced in Tasks 1 and 2 were shared with a range of stakeholders for their input (a full list of metrics is provided in Annex C). The groups consulted included leadership from the Tommy’s centres, staff from the pregnancy information service, trustees, and wider academic and clinical experts in the field. Each individual was sent the draft framework and metrics, and was then asked to provide their feedback in a one-hour interview with RAND Europe staff a few days later. Written comments were also provided in some cases.

Those consulted were broadly supportive of the overall framework but provided some specific pieces of feedback. These were collated into a spreadsheet, then the team used an internal workshop to analyse the overall feedback in relation to each part of the framework and the associated metrics, and made changes reflecting views expressed by the stakeholders where relevant. Key pieces of feedback which informed the changes to the framework and metrics are detailed in the following sections which set out the final framework. However, one piece of feedback received, which is worth noting here since it informs our data review, was that intermediate health outcomes should be considered alongside the ultimate measures of preterm birth, stillbirth and miscarriage. As well as consultation, we also conducted a review of maternal and neonatal datasets available in the United Kingdom (UK) to test the feasibility and framing of the metrics proposed for Tommy’s in terms of data availability. Key findings from that review are set out in the next two sections.
2.4.1. Data: Measuring stillbirth, preterm birth and miscarriage

Across all the work Tommy’s supports, the ultimate intended impact is to reduce rates of stillbirth, preterm birth and miscarriage. Therefore, a key element of our data review was to establish the main sources of evidence of this impact. These are set out below, along with caveats in terms of data quality and comparability. There are two other important caveats which apply more generally. Firstly, as raised by several stakeholders consulted, rates of stillbirth, preterm birth and miscarriage are interrelated. That is, a reduction in levels of miscarriage may well result in increases in levels of preterm birth or stillbirth. Secondly, miscarriage data is inevitably an underestimate of overall rates as many miscarriages, particularly those occurring early in pregnancy, will not be reported to health services. Indeed, for very early miscarriages, many women may be unaware that a pregnancy had occurred.

Availability of the data for measuring the ultimate impact on the number of babies who die during pregnancy and birth

To understand and assess the ultimate impact of Tommy’s work, rates of stillbirth, miscarriage and preterm birth across England, Wales and Scotland can be analysed. The data available for this analysis is as follows:

- Preterm birth and miscarriage data for England and Wales is available through the NHS England Maternity statistics data.9
- Stillbirth data for England and Wales in available through the Office of National Statistics (ONS) data on hospital maternity activity.10
- Preterm birth, stillbirth and miscarriage data for Scotland is available through NHS Scotland’s Information Services Division (ISD) Scotland website.11
- Additional data on Scotland is available through the Administrative Data Liaison Service Scotland.12

There is no unified data source across England, Wales and Scotland for measuring the ultimate impact in terms of reducing the number of babies who die during pregnancy or birth. The data for England and Wales is primarily available through NHS England and the ONS. The data for Scotland is available through the ISD. This means there can be differences in recording and classifying data on stillbirth rates, miscarriage rates and preterm birth rates. In addition, due to historical differences in how the data was maintained (and possibly also due to differences in digitisation of historical data), the datasets also appear to be split into different decades. Understanding all of these differences across datasets would require further investigation.

Finally, we note that there are significant gaps and variations in the data measured in England, Wales and Scotland. In England, barring London where detailed hospital-level data is available on maternity,

10 ONS (2017b).
11 ISD Scotland (2016).
12 ISD Scotland (2013).
miscarriages, preterm births and stillbirths, the granularity of data varies. As a result, the extent of ‘change in numbers’ and the associated factors which may influence this is difficult to ascertain definitively. Additional characteristics of these data sources are as follows:

- The NHS Maternity statistics\textsuperscript{13} also identify birth complications but this does not necessarily include deaths from birth complications.
- Hospital maternity activity ONS data\textsuperscript{14} includes historical data on stillbirths for England and Wales.
- ISD Scotland\textsuperscript{15} maintains data across various Scottish regions, including miscarriage data and stillbirth data, from 1998 to 2016.
- The Administrative Data Liaison Service Scotland\textsuperscript{16} maintains data from the Scottish Stillbirth and Infant Death Survey (SSBIDS) and includes causes of death for stillbirth, neonatal deaths and post-neonatal deaths. This data is available in patient non-identifiable form upon request.
- ONS data on childhood mortality\textsuperscript{17} contains data on early neonatal, neonatal, post-neonatal and infant (after 28 days) death, and perinatal death. However, in some cases, this data does not make a clear distinction between infant data and early childhood data.

2.4.2. Data: Measuring intermediate outcomes

As noted previously, many of the stakeholders consulted in the project noted that it may be valuable to look at intermediate pregnancy and maternal outcomes as part of the analysis of the effectiveness of Tommy’s work. This is because rates of stillbirth, preterm birth and miscarriage are low in the UK and as such, particularly on a local level, can be subject to significant variation from year to year. Looking at more common intermediate outcomes can therefore be helpful in terms of providing a more comprehensive understanding of the changes taking place over time. We have looked at the availability of data to support such analysis and note three potentially useful datasets for this type of analysis. A brief overview of each is provided below.

High-level assessment of the datasets and the information they offer

The information available through the NHS, ONS and ISD Scotland is in the form of number of total births, live births and still births at a regional level in England and Scotland. For large urban centres such as London, Manchester and Birmingham, the data is collected by the ONS and it differs on the parameters recorded by the ISD for Edinburgh. The information available on Wales does not have the same level of detail when city-locations are considered so the data is primarily at regional level.

\textsuperscript{13} NHS (2015).
\textsuperscript{14} ONS (2017b).
\textsuperscript{15} ISD Scotland (2016).
\textsuperscript{16} ISD Scotland (2013).
\textsuperscript{17} ONS (2017a).
Tommy’s has statistics on miscarriage rates. However, when considered in conjunction with the ONS, NHS England, and ISD Scotland data, the available data is about reported miscarriage levels and does not necessarily reflect actual (including unreported) miscarriage rates. Given the inability to account for unreported miscarriages, actual miscarriage rates can only be estimates.

In addition to the ONS, ISD Scotland and the National Records of Scotland (NRS), the three main sources of maternity and childbirth-related data are the Maternity Services Data Set (MSDS) published by NHS, the National Maternity and Perinatal Audit (NMPA), and the UK-wide Obstetric Surveillance Survey (UKOSS).

The MSDS includes data on:

- Age of mothers
- Total births
- Total babies
- Total mothers
- MBI
- Birth groups
- Smoking status (including number of cigarettes)
- Previous c-section
- Previous live births.

However, this data is limited to England and although it is available across various regions, it is incomplete when regions that do not include heavily populated city locations such as London, Manchester, or Birmingham are considered.

The NMPA publishes data across various maternity units in Scotland, England and Wales. However, units that do not pass the designated quality tests are not included and thus the data does not cover all units. This data is distinguished by individual maternity services (sites) and different maternity and neonatal services (measures).

This data can be analysed based on the following classifications: Site, Trust/Health Board, Region, and National/Country. For Site and Trust/Health Board, data can be selected based on a number of attributes including, for example, smoking cessation in pregnancy and elective deliveries before 39 weeks without a documented clinical indication, and babies born small for gestational age. Through the NMPA annual clinical report, clinical findings related the mother’s health after giving birth can also be accessed.

The UKOSS provides annual reports on uncommon pregnancy diseases across the various hospital units in the UK. For each hospital the data is available from 2015–16 onwards. However, this data is not

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18 Tommy’s (n.d.).
20 NMPA (2017a).
necessarily specific to childbirth-related complications. Examples of uncommon pregnancy diseases covered by the UKOSS data include:

- Amniotic Fluid Embolism
- Breast Cancer in Pregnancy
- Epidural Haematoma or Abscess Study
- Low Maternal Plasma Fibrinogen
- Seasonal Influenza in Pregnancy
- Spontaneous Haemoperitoneum in Pregnancy (SHiP)
- Cirrhosis in Pregnancy
- High Neuraxial Block in Pregnancy.

2.5. Logic model

2.5.1. Overall logic model
This section shows an overall logic model for the work of Tommy’s across the different aspects of the charity’s work. The overall intended impact across all elements of Tommy’s work is to reduce the number of babies who die during pregnancy and birth. However, the ways in which the different elements of Tommy’s work contribute to this are varied and as such the measures at the input, process, output and outcome level differ across those elements. It is also worth noting that different elements of the Tommy’s portfolio fall at different stages of the translational pathway. For example, the outcomes of the research centre and fellowship programmes, such as new understanding of the best ways to prevent preterm births, stillbirth or miscarriage, could form part of the inputs to the evidence-based, high-quality and comprehensive materials provided by the information service.

2.5.2. Inputs to the development of the logic model
A key input to the development of the logic model from consultees was that new intermediate outcomes should be considered, in the outcomes from the research centres and fellowships in particular, but by Tommy’s more generally. This is because the rates of the outcomes Tommy’s wish to address (stillbirth, miscarriage and preterm birth) are relatively low as a proportion of all births in the UK, so they are hard to assess and interpret, particularly at a local or regional level, because noise may obscure true trends in the data. As such, intermediate measures of maternal and birth outcomes can provide a useful dataset which might be more useful particularly for local or regional analyses.

2.5.3. The aim of the logic model
The aim of this logic model is to provide an overview of the aims of the different strands of Tommy’s work, and the pathways through which those aims are intended to occur. Looking at outcomes and

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Further information on logic models is provided in Annex A.
impacts in the context of this type of logic model is helpful in two ways. Firstly, it provides a useful resource to articulate the way in which the different activities of the charity contribute towards its ultimate aims with a range of stakeholders. To this end, we provide at the end of this section a possible ‘lay’ version of the framework that Tommy’s could use to communicate with a wider audience (Figure 2.7).

Secondly, the logic model format helps to address the challenge of attribution, whereby it is difficult to be sure that changes in the intended final outcomes and impact metrics are related to Tommy’s work. By showing the pathway through which those changes are to be achieved, and by being able to measure performance at each of those stages in the pathway, it becomes possible to show a feasible route through which the work supported by Tommy’s can contribute to changes in the ultimate rates of stillbirth, preterm birth and miscarriage, and evidence that those pathways are being realised.

In the following sections, we identify the impact metrics for the aims of different aspects of Tommy’s work and the pathways through which they could occur. We illustrate this through a series of figures, beginning with Figure 2.3. In these figures, the top row identifies the aims and the pathways. The bottom row identifies the impact metrics through which the aims and pathways could be measured.

**Figure 2.2 Overall logic model**

<table>
<thead>
<tr>
<th>Research Centre New Fellowships Scheme</th>
<th>INPUT</th>
<th>PROCESS</th>
<th>OUTPUT</th>
<th>OUTCOME</th>
<th>IMPACT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintain programmes of relevant, high-quality research</td>
<td>High-quality, relevant research conducted and published</td>
<td>Improved evidence base</td>
<td>New understanding</td>
<td>New understanding</td>
<td></td>
</tr>
<tr>
<td>Recruit high-quality fellows</td>
<td></td>
<td></td>
<td>New treatments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Implementation Centre</td>
<td>Set up centre and recruit staff</td>
<td>Understanding of how treatments succeed in health and social care system</td>
<td>Building evidence base in implementation</td>
<td>Increase in existing evidence being put into practice</td>
<td>Impact on policy</td>
</tr>
<tr>
<td>Fund projects</td>
<td>Building implementation capacity</td>
<td>Capacity to take up evidence based practice</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Set up portfolio of work and prioritise</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information Service</td>
<td>Provide evidence-based, high-quality, comprehensive information</td>
<td>People accessing Tommy’s information on our own channels</td>
<td>Better public understanding of healthy behaviours and care</td>
<td>Changed behaviours and lifestyle factors</td>
<td></td>
</tr>
<tr>
<td>Clinics</td>
<td>Provide funding for specialist staff</td>
<td>Enabling NHS-supported specialist clinics</td>
<td>Improved recruitment to clinical trials</td>
<td>Improved health outcomes</td>
<td></td>
</tr>
<tr>
<td>Allocate time for staff</td>
<td>Delivering high-quality care environment</td>
<td>Faster implementation of research findings</td>
<td>Develop evidence-based practice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provide infrastructure</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: RAND Europe
2.6. Possible metrics to measure the impact of the research centres and new fellowship scheme

This section outlines a set of possible indicators that could be used to evaluate the performance of Tommy’s research centres and the new fellowship scheme. As is the case for all the areas, it is not necessarily intended that all these indicators need to be collected at any one time. However, a combination of some of these metrics would likely provide useful evidence of the performance of these elements of Tommy’s work.

Key inputs from the stakeholders consulted that informed the development of this set of metrics and overall framework are as follows:

- Leveraged research awards (number and value) need to be considered as part of the framework.
- Career pathways for early career researchers should be considered (in terms of the proportion of them that are able to find independent funding and establish their own portfolio of research) to identify new leaders and evidence of capacity building in the field.
- The importance of intermediate outcomes in relation to the 'headline' impact needs to be recognised to assess the outcomes.

2.6.1. Data required for implementation of the impact metrics

In terms of implementation of the impact metrics, the majority of the data required could be requested as part of annual reporting of the centres (and fellows) to Tommy’s, and would likely be readily available to the centres based on our consultation. There are a few exceptions to this. Firstly, in the process section we include two options to measure the quality of the academic work conducted. The first is a bibliometric analysis of outputs. This requires a specialist bibliometrics provider to ensure that the data provided is subject to appropriate normalisation by field and year of publications. This would be best conducted at a charity level, but can carry a significant cost. Instead, Tommy’s may wish to ask experts to conduct a peer review of a sample of the academic outputs to provide an assessment of the quality of the work. There are recognised frameworks (e.g. that used in the Research Excellence Framework (REF)) that could be drawn upon for such analyses.

Second, there are indicators in the output section which require some effort to track, such as the careers of staff within and beyond Tommy’s funded research. For those within centres, career progression could reasonably be expected to be captured by the centres. However, for those moving on this might be more of a challenge, and might require some additional work by the Tommy’s team to track the trajectories of key individuals, and measures of their success and esteem.

Finally, under the outcomes indicator we note that citation in, or creation of, clinical guidelines might be an important indicator of changes in practice stemming from Tommy’s research. It may be that centres are aware of their contributions to such guidelines. However, our experience is that this is not always the case. There are a limited number of guidelines that are of relevance to Tommy’s work in the UK, so it may be feasible for Tommy’s staff to monitor changes and developments in these guidelines and check
whether new and revised guidelines include references to Tommy’s funded research. We have noted some of these guidelines below for further consideration by Tommy’s and the staff at the research centres.

2.6.2. Existing guidelines and advice that could be relevant to understanding references to Tommy’s funded research

The National Institute for Health and Care Excellence (NICE) has issued a number of guidelines related to pregnancy, maternity and infant care. The most relevant guidelines are identified below, with publication dates provided as footnotes.

**NICE pathways**

- Pregnancy
- Infants and Neonates

**NICE guidelines**

- Antenatal care for uncomplicated pregnancies
- Maternal and child nutrition
- Antenatal care
- Neonatal specialist care
- Postnatal care
- Preterm labour and birth
- Smoking: stopping in pregnancy and after childbirth.

In addition to the abovementioned NICE guidelines, Public Health England (PHE) public health safety updates related to infant mortality could also be considered relevant to understand citations to Tommy’s work. Examples of such advice include:

- Sudden unexpected deaths in infancy
- Reducing infant mortality.

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23 This is a collation of a number of NICE products related to pregnancy, infants and neonates.

24 NICE (2018a).


26 NICE (2008a).

27 NICE (2008b).

28 NICE (2012).

29 NICE (2010a).

30 NICE (2013).

31 NICE (2015).

32 NICE (2010b).


Figure 2.3 provides an overview of indicators related to the research centres and fellowship scheme.

### Figure 2.3 Possible indicators to measure impacts of research centres and new fellowship scheme

<table>
<thead>
<tr>
<th><strong>INPUT</strong></th>
<th><strong>PROCESS</strong></th>
<th><strong>OUTPUT</strong></th>
<th><strong>OUTCOME</strong></th>
<th><strong>IMPACT</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintain programmes of relevant, high-quality research</td>
<td>High-quality, relevant research conducted and published</td>
<td>Improved evidence base</td>
<td>New understanding</td>
<td>Reduce the number of babies who die during pregnancy or birth</td>
</tr>
<tr>
<td>Recruit high-quality fellows</td>
<td></td>
<td></td>
<td>New treatments</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>New and updated guidelines</td>
<td></td>
</tr>
</tbody>
</table>

**Research Centre**

**New Fellowships Scheme**

**Possible indicators**

- Number of applicants for positions/fellowships
- Number and value of leveraged research awards
- Perspectives of leading researchers and patient groups on prioritisation of research themes
- Peer review comments/scores on fellowship applications
- % planned research expenditure disbursed
- Bibliometric analysis of outputs (quality measured using mean normalised citation data and/or numbers of highly cited publications normalised by field)
- Annual peer review of outputs
- Volume and quality of publications in the relevant fields overall
- Retention of staff in the field
- Proportion of junior researchers receiving funding for their own independent research
- Increased investment in the field from other funders
- Esteem indicators such as awards and editorships
- Number of papers from centres and individuals cited in clinical guideline
- Number of new guidelines created informed by Tommy’s research
- Number, range and potential benefits (clinical/and cost effectiveness data, PREMs/PROMs) of new treatments
- Number of miscarriage, stillbirths or preterm births in the UK

Source: RAND Europe

### 2.7. Possible metrics to measure the impact of the implementation centre

This section sets out potential indicators to measure the inputs, processes, outputs and outcomes associated with the implementation centre which Tommy’s plans to establish. We anticipate that the majority of these indicators could be captured by the centre itself as part of annual reporting, subject to the caveats around bibliometrics and career tracking set out in the previous discussion of research centres and fellowships. However, a key limitation of our analysis here is that the implementation centre is yet to be established so we have had to make some assumptions about the likely activities and measurability of indicators for the centre. We recommend that this framework and the indicators should be revised and reviewed in collaboration with the centre team once the implementation centre is established.

We did, however, receive the following feedback from stakeholders consulted in relation to the indicators suggested for the implementation centre:

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35 Possible indicators highlighted in bold text are likely to be prioritised for implementation by Tommy’s.
• The scope of implementation of new/improved approaches needs to be broadened to include training for healthcare professionals (clinical practitioners including paramedics and nurses).

• The evidence base on early interventions (Patient Reported Outcome Measures (PROMs), Patient Reported Experience Measures (PREMs) or Quality Adjusted Life Years (QALYs)) needs to be identified to measure outcomes.

• Evidence of increased influence of best practices identified in implementation is needed to assess impact on policy.

These changes were discussed in the internal synthesis workshop as part of Task 3. These are included in Figure 2.4. One final note in relation to practical implementation of these indicators is that under outcomes we include two indicators which may be challenging to measure without additional (potentially significant) data collection. These indicators are:

• The number of individuals engaged with resources to support self-care and healthy behaviours;

• Evidence of increases in the proportion of care aligned to best practice.

In both cases, this might be possible through large-scale surveys of healthcare workers and providers or other providers of support to pregnancy and birth. This would be a significant effort to achieve at a national level. However, we anticipate that these are issues that an implementation centre might aim to address and investigate, and as such it may be that some of the work within the centre might aim to establish evidence on these important measures of implementation progress.

Figure 2.4 provides an overview of indicators related to the implementation centre.
2.8. Possible metrics to measure the impact of the pregnancy information service

This section sets out the range of possible indicators that could be used to establish the effectiveness of the pregnancy information service supported by Tommy’s. We are aware that most of the measures and metrics suggested here are readily available to the information services and could easily be collected and reported on an annual basis. However, we have made some suggestions about follow-up with users of services (particularly online resources) over the long term which could provide some evidence (albeit subject to some limitations in terms of response rates and potential response biases) about the ultimate outcomes of the service. In particular, we are aware that many users are subscribers who receive regular updates over the course of their pregnancy. We suggested that follow-up with those users after the due date of the pregnancy (which is typically provided by the user to inform the content they receive from Tommy’s) could become standard and that this could ask about not just birth outcomes, but also information on personal experience and feelings of self-efficacy, as well as the extent to which information from the information service helped individuals feel informed and able to act and practice healthy

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36 Possible indicators highlighted in bold text are likely to be prioritised for implementation by Tommy’s.
behaviours during pregnancy and birth. We also note that those using behavioural change tools (e.g. the caffeine calculator) could also be followed up not only immediately after using the tool in terms of their intention to act (as is currently done), but also at a later date such as 4–6 weeks later, to see if behaviours really did change. However, these types of analyses (as with other data collected through the website) might be subject to biases associated with self-reported survey data.

We received the following suggestions from stakeholders consulted in relation to the information service:

- The role of physical material (including leaflets) in dissemination (measure through the number of General Practitioner (GP) surgeries and thus the number of areas reached – particularly areas with higher miscarriage and stillbirth rates) would be crucial to estimating the reach.
- Follow-up with information service users to understand actual change in behaviour (and practice) that could contribute towards the ultimate impact would help better assess the outcomes.

These changes were discussed in the internal synthesis workshop as part of Task 3. These are included in Figure 2.5. We also produced a brief overview of other charities or organisations that offer support in relation to infant death child death-related situations. We reviewed website content in order to understand the impact reported by other organisations working in the field. The organisations covered as part of this review were:

- Care for the Family\(^{37}\)
- Child Bereavement Charity\(^{38}\)
- Cruse Bereavement Care\(^{39}\)
- Foundation for the Study of Infant Deaths (FSID)\(^{40}\)
- Stillbirth and Neonatal Death Society (SANDS).\(^{41}\)

A high-level examination found that none of these sites appear to publish information or statistics on their impact in the form of change in practice. It should be noted, however, that these charities are primarily engaged in post-hoc support rather than prevention, so their impact is not readily comparable to Tommy’s information service.

Figure 2.5 provides an overview of metrics related to the pregnancy information service.

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\(^{37}\) Care for the Family (n.d.).

\(^{38}\) Child Bereavement UK (2018).

\(^{39}\) Bereavement Care (2018).

\(^{40}\) The Lullaby Trust (2018).

\(^{41}\) SANDS (2017).
2.9. Possible metrics to measure the impact of the clinics associated with each research centre

This section sets out the range of possible indicators that could be used to establish the effectiveness of the clinics associated with each research centre. We also discuss the data sources that could be used to assess the metrics identified for the clinics. We anticipate that many of these measures would be readily available to the centres and could be included as part of annual reporting. However, we recognise that there may be exceptions to this.

We received some suggestions from stakeholders consulted in relation to the clinics. These include the following:

- Identifying the number of patients in the clinics with which Tommy’s works directly would be relevant to understanding the extent to which the clinics enable a high-quality care environment.
- The number of NHS staff trained in these clinics through Tommy’s work would be relevant to assessing the extent to which the clinics contribute to NHS-supported clinics.

Possible indicators highlighted in bold text are likely to be prioritised for implementation by Tommy’s.
• Measuring intermediate outcomes in terms of premature labours, neonatal and maternal morbidity would contribute to assessing the outcomes, specifically in relation to improved maternal health and related care as this can contribute significantly to the ultimate impact of saving babies’ lives.

These changes were included in the finalised version presented on the section following an internal synthesis workshop as part of Task 3.

2.9.1. Potential data sources that could be used to measure the metrics on intermediate outcomes and overall outcomes at the centre level

These metrics can potentially be measured through the data provided by the ONS and NRS. NMPA provides the data on specific units in places where Tommy’s centres are present.43

This covers the following units:

- London – St. Thomas’s Hospital KCL
- Edinburgh – Edinburgh Royal Infirmary
- Manchester – St. Mary’s Hospital
- Birmingham – The National Centre for Miscarriage Research.

The above data gives headline information including available cots, neonatal facilities and capacity. NMPA provides specific comparison data on these units.44 Specific mortality data on units in England and Wales is available at the ONS website.45 The data for Scotland on stillbirths and infant deaths for 2001–2016 is available at the NRS website.46 The ONS and NRS data do not specifically provide unit-level information but the information is available at regional and city level and can potentially provide a proxy for understanding impact.

2.9.2. Patient outcome/experience data

The granularity of this data varies across UK regions, so the extent to which these could contribute to understanding patient satisfaction at the level of hospitals/maternity units needs further investigation. However, a high-level understanding of patient satisfaction may be feasible based on following data sets:

- NHS England has data on Patient Experience scores which are available for 2013 onwards.47
- The Department of Health and Social Care provides the data on patient experience with NHS England prior to 2013.48

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43 NMPA (2017a).
44 NMPA (2017b).
45 See ONS (2017c) for further details.
46 See NRS (2018) for more details.
47 NHS England (n.d.).
NHS England provides the data for the GP patient survey (across the UK) which allows searches by practice and postcode.\textsuperscript{49}

NHS England also publishes data on outpatient and inpatient attendances, accident and emergency (A&E), and community mental health.\textsuperscript{50}

Figure 2.6 provides an overview of metrics related to the research centres.

**Figure 2.6 Possible indicators to establish the effectiveness of the clinics associated with each research centre\textsuperscript{51}**

<table>
<thead>
<tr>
<th>INPUT</th>
<th>PROCESS</th>
<th>OUTPUT</th>
<th>OUTCOME</th>
<th>IMPACT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinics</td>
<td>Provide funding for specialist staff Allocate time for staff Provide infrastructure</td>
<td>Enabling NHS-supported specialist clinics Delivering high-quality care environment</td>
<td>Improved recruitment to clinical trials Faster implementation of research findings</td>
<td>Improved health outcomes Develop evidence-based practice</td>
</tr>
<tr>
<td>Possible indicators</td>
<td>Amount of Tommy's staff time spent on delivering care Amount and nature of infrastructure and equipment available through the clinic Tommy's funding to the clinics</td>
<td>Levels of patient satisfaction compared to national averages Number of referrals for challenging cases (e.g. proportion of UK high-risk pregnancies referred to the centres) Retention and recruitment of high-quality staff (ideally compared to national averages) Number of patients seen in clinic Number of NHS staff trained</td>
<td>Evidence of changes in practice in centre -- number of patients receiving new improved treatments, patient feedback on those new treatments Number of individuals recruited to clinical trials Number of trials funded through other sources taking place within clinic</td>
<td>Evidence of better outcomes in centres (particularly miscarriages, stillbirths or preterm births) compared to national averages -- adjusted for case mix Evidence of better intermediate outcomes e.g. Number of premature labours, neonatal and maternal morbidity Evidence of dissemination of best practice to wider clinics -- number and effectiveness Changes to the way data is collected on patient outcomes (e.g. early vs. late miscarriages, health and wellbeing information on mothers)</td>
</tr>
</tbody>
</table>

Source: RAND Europe

2.10. Lay presentation of the framework

The overall framework not only serves as an evaluation tool, but can provide a representation of the work of the charity that can be communicated to wider audiences. To facilitate this, we have prepared an initial draft of a possible 'lay' version of the framework that could be used by Tommy’s in its wider communication work to illustrate the range of work it supports and how each element contributes to the

\textsuperscript{49} NHS England (2017a).

\textsuperscript{50} See NHS England (2017b; 2017c).

\textsuperscript{51} Possible indicators highlighted in bold text are likely to be prioritised for implementation by Tommy’s.
overall aims of the charity. This is a draft representation and would require testing and refinement with patients and members of the public to ensure it is relevant, clear and appropriately worded for wider communication purposes.

**Figure 2.7 Lay presentation of the framework**

[Diagram showing the framework with sections labeled: What Tommy's supports, What they do, Intended results, and Fewer babies die during pregnancy and birth.]

Source: RAND Europe
References


Care for the Family. n.d. ‘Because family life matters’. Care for the Family. As of 2 July 2018: https://www.careforthefamily.org.uk/


NPEU. 2018. ‘UK Obstetric Surveillance System (UKOSS)’. National Perinatal Epidemiology Unit, 25 April. As of 2 July 2018: https://www.npeu.ox.ac.uk/ukoss


Impact assessment frameworks are typically most useful when they take account of the wider system that is contributing to them. We therefore adopt an approach which looks at how impacts are being achieved, not just whether they are realised or not. A theory of change is used as the foundation of the approach. The theory of change sets out the building blocks needed to deliver on organisational goals, through a pathway of interventions, and based on a range of assumptions about the underlying logic and types of interventions which can lead to desired results.\textsuperscript{52} Theories of change tend to be valued in planning and evaluation because they help create a shared view of what the vision and strategy is, how it will be pursued, and what can be done to assist in identifying measures for capturing learning and reflecting on progress. Articulating a theory of change and specifying the intervention logic can allow for a thorough examination of expectations from the perspectives of multiple stakeholders.

Once the theory of change is established, a ‘logic model’ is used to assess whether the organisation is taking steps in the near and medium term to meet its longer-term goals. Logic models aim to consider the key ingredients of the organisation in terms of what inputs and processes are needed now in order to achieve desired outputs and outcomes, or results, in the future.\textsuperscript{53} Figure A.1 below illustrates a generic logic model. A logic model is a way of articulating a causal pathway by which an organisation achieves its aims, and identifies outcomes that can be causally linked back to concrete inputs. The following is a high-level description of the main categories of the ingredients of an organisation as depicted in Figure A.1:

- **Inputs** into the programme that is being implemented (e.g. financial, staff, physical, relational resources needed to pursue programme objectives);
- **Activities or ‘processes’** through which programme aims and objectives are being pursued (e.g. activities related to capacity building, research, education, etc.);
- **Expected outputs** – direct shorter-term achievements from the programme (e.g. numbers of researchers trained, new postgraduate training programmes in institutions);
- **Expected outcomes and impacts** – longer-term expected consequences of the programme (e.g. improved research career prospects in institutions, strengthened grant management policies and practices, increased ability to obtain third-party funding for research and capacity-building activities);

\textsuperscript{52} A ‘theory of change’ is an evaluation framework used in many different contexts. See for example: Weiss (1995); Connell and Kubish (1998); Marjanovic et al. (2012); Pawson and Tilley (1997).

\textsuperscript{53} van Dijk (2009).
• *Processes* – these include both higher-level elements of a strategy, and more detailed activities through which the strategy is being implemented.

The layout of Figure A.1 is as follows:

• The left-most column (in blue) indicates the different parts of the organisation which are being evaluated through the logic model.

• The rows (in grey boxes) indicate the metrics or indicators against which the different parts of the organisation would be evaluated.

This kind of matrix also provides the basis for developing indicators in a robust, methodical way. The advantage of this structure is that it forces the dashboard to include ‘non-obvious’ and ‘hard-to-measure’ indicators (along with ‘obvious’ and ‘easy-to-measure’ indicators). This results in a diverse but representative set of key impact indicators which can be used to measure impact performance. This method of developing indicators around multiple goals is used by industry, government and non-profits.

**Figure A.1 High-level representation of logic models**

![Figure A.1](source: RAND Europe)
Annex B. Challenges in measuring impact

This section sets out the key challenges in measuring impact for any given set of metrics. We discuss the challenges, how these relate to Tommy’s objectives, and possible ways in which these could be mitigated with the logic model being proposed. For the following discussion, we draw on a number of previous studies conducted by RAND Europe.54

B.1. Contribution and attribution

The challenge of any system that assesses impact is to ensure that there is a clear and shared understanding of the difference between ‘contribution’ and ‘attribution’. By contribution we mean understanding how the investment has contributed to a set of benefits or impacts. This is opposed to the extent to which the benefits and impacts can be attributed to any single activity. In this way, when considering attribution, we are referring to the proportional effort made by a funder to the creation of the outputs. Contribution is reflective of the ability to claim a role in particular outputs, regardless of the relative amount of that contribution. For example, we are aware that Tommy’s provides some support to their centres, but that they also receive significant other sources of research funding. One approach would be to consider the proportion of the centres’ funding that comes from Tommy’s, and attribute a proportion of the benefit accordingly. However, this is somewhat reductive. A better approach might be to note that the support made a contribution to the overall outcomes of the centres, or, even better, seek to establish the counterfactual – that is, what would the consequences have been if that core centre funding were not available.

The logic model approach allows us to dig deeper into the causal mechanisms which lead to impact, including where there are direct impacts attributable to Tommy’s, and where there is the need to work with other stakeholders to collectively achieve impact and where Tommy’s plays play a role in contributing to this achievement.55

B.1.1. Time lags

Time lags involved in impact are one of the most crucial challenges in impact assessment. The first step is to recognise what the expected time lags are for different types of impact, so that expectations are set

54 Morgan Jones and Grant (2013); Guthrie et al. (2013); Morgan Jones et al. (2017).
55 See Morgan Jones and Grant (2013) for more details on ‘contribution’ and ‘attribution’.
appropriately. Again, a logic model can be helpful here as it provides indicators of the process towards achieving longer-term impacts and provides a sense of whether shorter-term goals are being met.

B.1.2. Non-linearity of impact

In addition to the time taken to realise impacts, it is possible that impact may not be realised in a temporal, linear manner and may be subject to the unpredictability of socio-economic and political changes. For impacts that happen over longer durations of time and have complex pathways, impact assessment can prove challenging. In this context, logic models can enable the outcomes that may occur in interrupted time cycles to be understood in advance and allow the impact assessment to accommodate the cyclical, non-sequential nature of the outcomes.56

B.1.3. Availability and quality of data

When impact assessments rely on existing data sets, the effectiveness of the assessment is subject to the reliability, validity and accuracy of the data sources, including the results provided by methods such as data mining. Where qualitative approaches such as case studies are used, the impact assessment needs to appropriately triangulate and validate the data collected. In such a context, when used in conjunction with a review of the available data sets, a logic model can set out indicators that are measurable and also help identify the need for further stakeholder engagement for indicators that are necessary to measure the impact, but would require new sets of data to measure. This approach also brings together different approaches to measurement, which allows comparison and testing of findings across different data sources.57

B.1.4. Communication

Just as impacts can occur in a range of ways, they can also be captured and measured in different ways. Some aspects of impact such as reach (e.g. number of patients, number of staff, etc.) may be readily measurable and thus easy to communicate. However, impacts that cannot be explained in terms of linear progression of outcomes or are inherently qualitative in nature (e.g. patient experience or behavioural changes) may prove difficult to communicate to a general audience. A logic model allows such complex indicators of impact to be identified and can enable Tommy’s to plan for dissemination of such outcomes accordingly. It is also important to note that although this model focuses on quantitative measures, case studies setting out the ‘story’ of impact and personalising the measures for people can be very powerful with many audiences, notably patients, the public and policymakers.58

56 See Morgan Jones et al. (2017) for more details on non-linearity of impact.
57 See Guthrie et al. (2013) for more details in availability and quality of data.
58 See Morgan Jones et al. (2017) for more details on communication of impact.
Annex C. Longlist of metrics based on a review of the literature

The metrics in this longlist were identified on the basis of their relevance to different aspects of Tommy’s work (i.e. research centres, implementation centre, information service, clinics) and the extent to which they could contribute to measuring the ultimate impact targeted by Tommy’s. The metrics are not listed in a specific order. The main sources of literature for this longlist are a recent review of evaluation frameworks,59 and prior work by RAND Europe for THIS Institute on the measurement of improvement research (in press).

Table C.1. Longlist of metrics based on a review of the literature

<table>
<thead>
<tr>
<th>Metric</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of staff (PhD students, researchers, members of staff)</td>
</tr>
<tr>
<td>Number of applications for fellowships</td>
</tr>
<tr>
<td>Reviewer scores of fellowship applications</td>
</tr>
<tr>
<td>Number of applications from international candidates</td>
</tr>
<tr>
<td>Gender balance and diversity of applicants</td>
</tr>
<tr>
<td>Satisfaction of Tommy’s stakeholders with the research funded</td>
</tr>
<tr>
<td>Practitioner and patient perspectives on the relevance of the proposed programme of research (e.g. through survey)</td>
</tr>
<tr>
<td>Satisfaction of staff and participants (at different levels) with the management and government systems</td>
</tr>
<tr>
<td>Measures of turnaround times for decision-making and administrative processes (to be determined which these should be internally)</td>
</tr>
<tr>
<td>Staff turnover</td>
</tr>
<tr>
<td>Academic collaborations/research networks/data sharing</td>
</tr>
<tr>
<td>Collaborative research with industry</td>
</tr>
<tr>
<td>Staff movement between academia and industry</td>
</tr>
<tr>
<td>Staff movement between academia and NHS</td>
</tr>
<tr>
<td>Number and range of practitioners engaged in each of the following project stages: prioritisation and idea</td>
</tr>
</tbody>
</table>

59 Raftery et al. (2016).
Metric development; project planning; creation of research materials; data collection; data analysis; reporting.

Number of fellowships completed

Number and quality of publications of fellows (quality measured using mean normalised citation data and/or numbers of highly cited publications normalised by field)

Number and quality of publications from Tommy’s (quality measured using mean normalised citation data and/or numbers of highly cited publications normalised by field)

Number of speaker invitations/conference invitations (academic and practitioner)

Outreach: Co-author analysis, field analysis of citations

Development of research leaders (e.g. number of published authors/people named on grants)

Academic careers advancement

References used as background for successful funding proposals

Feedback from clinics/parents (e.g. by survey) on the relevance of research to their practice.

Number (and range) of references in materials aimed at patient and staff audiences (e.g. patient group materials, practical toolkits).

Number of times research outputs accessed/ downloaded

Key contributions to the creation, development and maintenance of major research resources (e.g. health information systems, software, databases)

Research cited in advocacy publications

Number of editorships of high profile journals

Number of Tommy’s researchers on research boards/committees

Reporting of research in the news/media (e.g. number and type of press releases, Tweets, blogs)

Number and nature of awards and prizes to Tommy’s researchers

Number of Tommy’s researchers in senior research positions – e.g. professors

Next destinations of fellows – proportion staying in prenatal research

Number of citations in systematic reviews

Compliance and adherence to research-informed policies and guidelines

Addressing barriers to the use of research-informed interventions in the health system

Improved patient satisfaction

Reduced adverse events/complications

Cost savings/cost reduction in delivery of existing services

Interactions between researchers and policymakers/strong and ongoing links with policymakers and advocacy groups

Website hit rate

Improved research literacy among health staff

Number and range of participants to events
Metric

Level of response to media coverage
Strong and ongoing links with clinicians
Number/proportion of Tommy’s research publications with an NHS-based author
Number and range of NHS staff who are involved in research
Number and range of NHS maternity and neonatal staff who consider research a core part of their role
Number of NHS staff who have had training in research (of some form).
Number of citations in policy documents
Number of citations in clinical guidelines
Number of citations in ongoing health professional education material
Number of presentations to policy and decision makers
Number of invitations from policymakers
Number/size of requests for research to support policy
Number of citations in curricula for new researchers
Number of Tommy’s researchers on key boards and committees (e.g. NICE, PHE)
Increased service effectiveness
The use of Tommy’s research evidence by different groups involved in clinical diagnosis and decision-making
Economic benefits from improved maternity and birth outcomes
Proportion of centre research conducted with NHS partner
Long-term increases in quality of research as indicated bibliometrically or through submissions of maternity and implementation research in REF
Number/scale of large-scale (long-term) programmes and units funded in implementation research
Numbers of available formalised career tracks around maternity research, and uptake of these
Changes in clinical practice based on implementation research (likely qualitative evidence)
Field-normalised citation impact and numbers of highly cited papers
Additional funding leveraged by the research centres
Amount of funding Tommy’s invests into a centre
The production of a database or collection of data
Impacts of Tommy’s funded research on improving training in the field of interest
Impact of Tommy’s funded research on career development of experts in the field
Researchers may receive promotions
New research groups founded
Sustained or increased in size
Prizes or awards for research may have led to career advancement
Research has been included in clinical guidelines, a Cochrane or Campbell review, clinical reviews (such as
Metric

those published in the Lancet or BMJ, or other policy documents (e.g. government white papers)

Giving evidence to a government review or a parliamentary

Membership or chairmanship of a guideline committee

Number of pregnancies coming to full term with positive outcomes

Number of reviews

New or changes in existing products

Patents

Further research

Research update and translatability – patents, clinical trials, partnerships with other sectors

Number of research projects managed

Public recognition (awards/fellowships)

Academic career advancement

Evidence modifying research priorities/resource allocation strategies/linking research to other disciplines

Academic collaborations/research networks/data sharing

Changes in practice

Changes in terminology

Patient reported outcome measures (PROMS)

Patient satisfaction and experience surveys

Qualitative data on waiting times and service accessibility

Adoption of health technologies

Research outcomes to improve healthcare systems and inform policies and guidelines

Cost-effectiveness assessment of introducing a new health technology

New funding attributed to intervention

Better targeting, accessibility, utilisation and coverage of health services

NHS Choices end-user visit rate

Level of public engagement with science and research

Improved care – from trials

Health literacy – ability of patients to make informed healthcare decisions

Development and sale of spin out companies

Licences awarded and brought to market

Amount of R&D funding awarded by NHS and other organisations

Completion rates of fellowships

Number of research projects engaging community partners
<table>
<thead>
<tr>
<th>Metric</th>
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<tbody>
<tr>
<td>Number of articles co-authored with community/NHS partner</td>
</tr>
<tr>
<td>Number of staff engaged in outreach</td>
</tr>
<tr>
<td>Level of participation in clinical trials</td>
</tr>
<tr>
<td>Number of projects with industry partner</td>
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<tr>
<td>Number of citations in clinical guidelines</td>
</tr>
<tr>
<td>Number of citations in policy documents</td>
</tr>
<tr>
<td>Improved health of patients</td>
</tr>
<tr>
<td>Improved quality of care metrics</td>
</tr>
<tr>
<td>Numbers of lives touched</td>
</tr>
<tr>
<td>Narrowing of health/health care disparities</td>
</tr>
<tr>
<td>Improved awareness of preventative measures in the community</td>
</tr>
<tr>
<td>Number of treatments developed in house</td>
</tr>
<tr>
<td>Number of new treatments available (adopted from elsewhere)</td>
</tr>
<tr>
<td>Percentage/number/range of types of clinicians on research projects</td>
</tr>
<tr>
<td>Number of uses of research infrastructure in clinical practice</td>
</tr>
<tr>
<td>Number of and list of new treatments</td>
</tr>
<tr>
<td>Perceptions of staff</td>
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<tr>
<td>Perceptions of community partners</td>
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<tr>
<td>Perception of external experts</td>
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<tr>
<td>Perceptions of people participating in research</td>
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<tr>
<td>Attitudes of research participants toward research</td>
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<tr>
<td>Start-up time for research projects</td>
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<tr>
<td>Improved quality of care metrics</td>
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<tr>
<td>Numbers of lives touched</td>
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<tr>
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<td>Metric</td>
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<tr>
<td>Attitudes of research participants toward research</td>
</tr>
<tr>
<td>Start-up time for research projects</td>
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<tr>
<td>Start-up time for clinical trials</td>
</tr>
<tr>
<td>Proportion of articles that are open access</td>
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<tr>
<td>Proportion of projects that consider health equity in their design and conduct</td>
</tr>
<tr>
<td>Survey of public health policymakers</td>
</tr>
<tr>
<td>Consulting to industry</td>
</tr>
<tr>
<td>Use of research in stage reports by industry</td>
</tr>
<tr>
<td>Public lectures given</td>
</tr>
<tr>
<td>Prevalence, incidence, QALYs, patient reported outcome measures</td>
</tr>
<tr>
<td>Adherence to clinical guidelines</td>
</tr>
<tr>
<td>Number of industry funded trials taking place within institute/clinic</td>
</tr>
<tr>
<td>Total value of industry funded trials taking place</td>
</tr>
<tr>
<td>Recruitment to trial performance</td>
</tr>
<tr>
<td>% planned research expenditure disbursed</td>
</tr>
<tr>
<td>% applications deemed funded that were funded</td>
</tr>
<tr>
<td>% of publications in journals targeted at practitioners</td>
</tr>
<tr>
<td>Pages accessed on website</td>
</tr>
<tr>
<td>Number of parents/babies treated in clinics</td>
</tr>
<tr>
<td>Reach of health information (paper/digital)</td>
</tr>
<tr>
<td>Number of calls to info line</td>
</tr>
<tr>
<td>Coverage of new interventions (reach, access, spread, penetration)</td>
</tr>
<tr>
<td>Measures of active management of pregnancy</td>
</tr>
<tr>
<td>Availability of equipment and facilities</td>
</tr>
<tr>
<td>Proportion of pregnant women engaged with research</td>
</tr>
<tr>
<td>Number of service delivery hours for users served</td>
</tr>
<tr>
<td>Number of hours of professional activities (carried out for training, education, i.e. not with user)</td>
</tr>
<tr>
<td>Number of users waiting for initial service</td>
</tr>
</tbody>
</table>

Source: RAND Europe analysis
Annex D. Participants in the stakeholder consultation

All of the consultations were conducted via telephone in the form of a semi-structured interview. All of the participants identified here have confirmed their willingness to be named as part of this annex in this report. Participant names are listed in ascending alphabetical order based on their last name.

Table D.1 Participants in the stakeholder consultation

<table>
<thead>
<tr>
<th>Participant</th>
<th>Stakeholder’s role/engagement with Tommy’s</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anita Charlesworth</td>
<td>Director of Research and Economics, The Health Foundation</td>
</tr>
<tr>
<td></td>
<td>Honorary Professor in the College of Social Sciences at the Health Services Management Centre, University of Birmingham</td>
</tr>
<tr>
<td></td>
<td>Member of Tommy’s board of trustees</td>
</tr>
<tr>
<td>Arri Coomarasamy</td>
<td>Professor of Gynaecology at the Institute of Metabolism and Systems Research, University of Birmingham</td>
</tr>
<tr>
<td></td>
<td>Director of Tommy’s National Centre for Miscarriage Research</td>
</tr>
<tr>
<td>Kate Davies</td>
<td>Tommy’s Marketing Director</td>
</tr>
<tr>
<td></td>
<td>Heads the pregnancy information services and pregnancy information campaigns</td>
</tr>
<tr>
<td>Tim Draycott</td>
<td>Consultant Obstetrician, NHS North Bristol Trust</td>
</tr>
<tr>
<td></td>
<td>Developed a safer delivery model for Tommy’s</td>
</tr>
<tr>
<td>Alexander Heazell</td>
<td>Clinical Senior Lecturer, Maternal and Foetal Health Research Centre, School of Medical Sciences, University of Manchester</td>
</tr>
<tr>
<td></td>
<td>Clinical Director of the Tommy’s Stillbirth Research Centre</td>
</tr>
<tr>
<td></td>
<td>Leads the stillbirth research theme at the Maternal and Foetal Health Research Centre</td>
</tr>
<tr>
<td>Jane Norman</td>
<td>Professor of Maternal and Fetal Health, University of Edinburgh</td>
</tr>
<tr>
<td></td>
<td>Director of Tommy’s Research Centre in Edinburgh</td>
</tr>
<tr>
<td></td>
<td>Deputy Director Centre for Reproductive Health, University of Edinburgh</td>
</tr>
<tr>
<td>Lucilla Poston</td>
<td>Tommy’s Campaign Professor of Maternal and Foetal Health, King’s College London</td>
</tr>
<tr>
<td></td>
<td>Scientist appointed chair of Tommy’s</td>
</tr>
<tr>
<td>Kate Smaje</td>
<td>Senior Partner, McKinsey &amp; Co.</td>
</tr>
<tr>
<td>Participant</td>
<td>Stakeholder’s role/engagement with Tommy’s</td>
</tr>
<tr>
<td>-------------------</td>
<td>-----------------------------------------------------------------</td>
</tr>
<tr>
<td>Gordon Smith</td>
<td>Works on digital transformation</td>
</tr>
<tr>
<td></td>
<td>Member of Tommy’s board of Trustees</td>
</tr>
<tr>
<td>Angela Spatharou</td>
<td>Professor and Head Of Department, Department of Obstetrics and Gynaecology, University of Cambridge</td>
</tr>
<tr>
<td></td>
<td>Partner, McKinsey &amp; Co</td>
</tr>
<tr>
<td>Helen Williams</td>
<td>Has been a consultant for NHS providers on service redesign, quality, care integration and productivity</td>
</tr>
<tr>
<td></td>
<td>Research Associate, Institute of Metabolism and Systems Research, University of Birmingham</td>
</tr>
<tr>
<td></td>
<td>Supports Tommy’s National Centre for Miscarriage Research, Birmingham</td>
</tr>
</tbody>
</table>