ALL WALES COMMUNITY CARDIOLOGY EVALUATION

Impact Evaluation Framework

for British Heart Foundation and All Wales Cardiac Network

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1. INTRODUCTION

The Welsh Institute for Health and Social Care (WIHSC), University of South Wales was commissioned by the British Heart Foundation to evaluate how the community cardiology funding from the Welsh Government has been utilised and explore whether the proposed new services and pathways have been realised.

This paper provides information about one of the key outputs from the study – the development of an All-Wales Community Cardiology Impact Evaluation Framework (IEF).¹ WIHSC was specifically asked to support the Heart Conditions Implementation Group (HCIG) and the health boards in this work so that they are: *well-equipped and informed to plan and conduct an impact evaluation of their services and monitor patient outcomes themselves. We would expect this to involve helping with identification of datasets and key metrics and analysis tools for undertaking an impact evaluation.*²

Accordingly, this document contains an account of the genesis of the IEF, and the detail of the framework itself.

CONTEXT

When the Welsh Government made available the annual £850,000 to provide community cardiology services, six health boards were successful in making applications for this money which was distributed on a per capita basis across Wales. The Welsh Government set down six key objectives against which the funded community cardiology services were expected to deliver:

- 1. Ensure patients receive cardiology diagnostics and effective treatment in a timely manner
- 2. Improve access to primary care, and support a shift into community care
- 3. Support activity to sustainably improve patient flow and waiting lists
- 4. Deliver substantial planned pathway improvements, and reducing avoidable pressure on unscheduled care
- 5. Reduce admissions and re-admissions to hospital
- 6. Add to the evidence base on innovation in community cardiology

It should be noted, however, that when beginning to put in place the new services, health boards were working in the absence of a defined national pathway, and that underneath the six headline objectives, there were no targets, key performance indicators or measures issued. There was a degree of flexibility in how different areas interpreted different aspects of their new services, and the six sites all took different approaches to the nature of what constitutes community cardiology – one service model size did not fit all. Further, there was an asymmetry in the starting points and

¹ The other key output is a formative evaluation of the process of implementation of the six community cardiology services across Wales.

² Statement taken from the BHF specification for the community cardiology evaluation study.

history of such community services across Wales. Accordingly, those delivering services started to collect data on the impact of their services without clear guidelines, and as such there was no consistency of approach between the six services.

METHOD

In this context, the study team went through a series of stages that the before arriving at the final IEF as described in this document.

1. Identifying relevant source material for the IEF

There were a number of principles that informed our review of literature at the outset of the study:

- Identifying both qualitative and quantitative methods and approaches to measuring the impact of community cardiology;
- Looking to understand what the key guidelines recommend;
- Learning lessons that can be applied to Wales from the commissioning of services and contract monitoring in other health economies; and
- Recognising relevant features in the recent history of performance management in Wales.

Guidance from NICE,³ the British Cardiovascular Society,⁴ the Wales Cardiac Network⁵ and a number of NHS England sites (for example Brent and Rochdale^{6,7}) was accessed and evaluated. The 'Welsh approach' to Quality Improvement (take account of local and historical context to arrive at measures that offer opportunities to measure progress that are relevant and appropriate) was applied.

Materials in personal archives relating to the development of a performance management Framework for Primary Care in Wales in 2002-2003 together with key ideas from a Kings Fund publication in 1999⁸ and presentations by the Deputy Chief Medical Officer, Dr Chris Jones, and Dr Alberto Zanobini from Tuscany to the 2013 Public Health Wales Annual Conference⁹ informed our thinking. This focused especially on how to develop a 'Transformation Matrix' building on the 'Maturity Matrix' concept, first developed in Wales.¹⁰

³ <u>https://www.nice.org.uk/guidance/cg180/</u>, <u>https://www.nice.org.uk/guidance/cg108/</u>

⁴ <u>http://www.bcs.com/documents/B1Z_BCS_Statement_GPwSI_May10.pdf;</u>

https://www.bcs.com/documents/Commissioning%20of%20Cardiac%20Services%20-%20Appendix%20A.pdf

⁵ <u>http://www.wcn.wales.nhs.uk/home</u>

⁶ <u>http://brentccg.nhs.uk/en/publications/doc_download/700-cardiology-service-specification&usg=AOvVaw0hC6xjGPFKQE6W9uuXgLG1</u>

⁷ https://www.hmr.nhs.uk/attachments/article/286/PAPER%2010%20CCG%20GB%20ICCS%20front%20sheet.pdf

⁸ Greenhalgh T, Eversley J (1999) *Quality in General Practice* Kings Fund. London.

⁹ http://www.wales.nhs.uk/sitesplus/888/page/66731#presentations

¹⁰ Elwyn G, Rydderch M, Edwards A et al (2004) Assessing organisational development in primary medical care using a group based assessment: the Maturity Matrix[™] *BMJ Quality & Safety* **13**:287-294 <u>http://qualitysafety.bmj.com/content/13/4/287</u>

2. Engagement with clinicians

The study team recognised the importance of engaging with clinicians throughout the study. Indeed the team itself was complemented by the expertise and skill of a former consultant cardiologist who had experience of providing community cardiology services (Dr Rhid Dowdle), and a former GP and health board clinical director who had been involved in developing innovative services models in the community throughout his career (Professor Jonathan Richards).

Once the first version of the IEF had been completed, two workshops were held to gather feedback from clinicians who are engaged in directly providing community cardiology services (whether GPs or other practitioners), consultant cardiologists, general managers within cardiac services, and a range of others.¹¹

The first version of the IEF included a set of quantitative measures and metrics across a number of aspects of clinical practice. A very valuable set of comments was received from these groups, which challenged some of the premises upon which the IEF had been developed to that point. These issues centred on five main areas:

- 1. COHORT: Should the IEF relate to all community cardiology patients, or only to those that go through particular named 'clinics', or only the six funded CC services?
- 2. SAMPLING: Should we sample the patient cohort for the IEF or use the whole cohort of patients once that cohort is determined?
- 3. QUANTITATIVE ↔ QUALITATIVE: Did we have the right balance between quantitative measures within the IEF?
- 4. TRANSACTIONAL ↔ TRANSFORMATIONAL: Did we have the right balance between the transactional and transformational elements of the CC services?
- 5. FREQUENCY: How regularly should the IEF be completed? Annually to WG? More frequently for HBs (especially if data systems can be automated)?

These challenges required the study team to reflect and to iterate the IEF accordingly.

3. Iteration of IEF from one to three elements

Having spent time thinking through the implications of the feedback from the clinician workshops, the study team concluded that two key things needed to change.

The first was that the quantitative measures needed to be complemented by a more qualitative form of assessment of impact. It was suggested by the clinicians that not everything could be adequately measured in numerical form, and so the study team developed a 'Transformation Matrix' (using a Maturity Matrix approach) to take account of this gap.

The numbers of patients seen, investigations carried and interventions performed within each Health Board do not tell the whole story about the transformative opportunities provided by the

¹¹ Twenty-one people contributed to these two events – one of which was a teleconference held between North Wales and Merthyr Tydfil, and the other a face-to-face meeting held in Bridgend.

new resources made available in this initiative. The Maturity Matrix is helpful in displaying key components of the development of an activity, programme or team.

Clinical Records	Audit of clinical performance	Clinician access to clinical information	Use of guidelines	
50%	50%	50%	50%	
Written records only. No computerised information.	Audits not undertaken	No clinical information available in practice	Guidelines not used within the practice	Þ
Registration data on computer.	Data collection exercises completed but failure to meet full audit cycle criteria.	Textbook access, limited locations.	Guidelines discussed but no policy to follow any particular guidelines agreed	Presci and o
Registration and repeat prescribing system on computer.	Less than one audit per year that meets full audit cycle criteria.	Peer reviewed journals e.g. BMJ and similar available to all clinicians.	Guidelines discussed and adapted to use in the practice	Prescr and c to e.g. i
Electronic records kept for registration and prescriptions.	Regular audit cycles completed but only few clinical areas.	Peer reviewed journals and digest publications such as Bandolier, Effective Healthcare Bulletins, Drug & Therapeutics Bulletin available to all clinicians.	Guidelines are incorporated into clinical information systems and used as clinical tools.	Aware loc mod
Mix of electronic and paper records	Regular full audit cycles undertaken in key clinical areas (asthma, diabetes, hypertension)	On-line access to internet based databases available to all clinicians at limited locations.	Use of guidelines audited.	Pres chan wi
Majority of clinical encounters coded electronically by clinicians (i.e. searchable).	Regular full audit cycles undertaken in key clinical areas (asthma, diabetes, hypertension) and information regarding audits published for external peer review, e.g. to audit groups.	On-line access to information at clinical desktops.	Care pathways developed and implemented.	Arı F phar impl prese

(Figure taken from Elwyn G et al, 2004)¹²

Maturity Matrices are the foundation of the Clinical Governance Practice Self-Assessment Tool, used by all general practice teams in Wales as a component of the Quality and Outcomes Framework. A Matrix can be used to decide on which domains of activity to prioritise, what objectives to aim for and how key components of a Quality Improvement programme can be linked together (structure, process, resources, outcomes for example).

Each column or pair of columns provides an opportunity for Cardiology Teams to discuss their achievement together with a narrative to provide more detail and local colour. There may be ticks in more than one row and column. Teams can learn by discussing their Matrices. Often people will have different perspectives on achievement and progress, and different priorities. The discussions can raise significant blocking or facilitating issues.

¹² Elwyn et al., op. cit

The second was that more thought needed to be given to concepts of value-based healthcare, in line with the Prudent Healthcare principles, which would allow the six services to come to a view about notions of cost, benefit and value for money.

The WIHSC team was asked specifically to suggest ways of measuring 'Value-Based Healthcare'. This is a core component of the Prudent Healthcare initiative¹³ and the work of the Bevan Commission.¹⁴ This work is gathered together by NHS England as 'NHS Rightcare'¹⁵. The Kings Fund published a helpful report on the issues in 2015,¹⁶ and the Health Foundation¹⁷ published a worked example in 2015. The Health Foundation Report mentions an essay in the New England Journal of Medicine,¹⁸ and consequently defines value-based healthcare as: Health Outcomes ÷ Cost. The worked example started with their approach to values and value, in effect through developing and implementing a new system of 'value-based reporting' of which the key components were defined as:

- a new method of value data capture;
- a set of new value-based reporting tools; and
- a value-based management system.

In Wales, there is a worked example of Value-Based Healthcare in practice which has been developed by the Aneurin Bevan University Health Board.¹⁹ The key lessons from their work are useful to inform this IEF – and they conclude that:

- External help and expertise can make a difference;
- The whole organisation should be involved actively in discussions and determinations around value-based healthcare;
- Clinicians, managers and the finance team have to learn together;
- A fundamental component of establishing value and outcomes is the development and agreement of patient and management pathways as this enables opportunities for change to be clearly identified and costs accurately compared; and
- Eliciting patient opinions provides essential perspectives on priorities and delivery.

As an outcome of all of this additional work, the iterated IEF was re-designed to include three elements: a transformation matrix, a core dataset, and an accompanying narrative (detail is provided in Chapter 2 below).

¹³ <u>http://www.prudenthealthcare.org.uk/</u>

¹⁴ <u>http://www.bevancommission.org/</u>

¹⁵ <u>https://www.england.nhs.uk/wp-content/uploads/2017/02/board-papers-090217-item-6-nhs-rightcare.pdf</u>

¹⁶ <u>https://www.kingsfund.org.uk/publications/better-value-nhs</u>

¹⁷ <u>http://www.health.org.uk/programmes/shared-purpose/projects/value-based-reporting-and-management</u>

 ¹⁸ Porter ME (2010) What Is Value in Health Care? *N Engl J Med* 2010; 363: pp.2477-2481 – DOI:
 10.1056/NEJMp1011024 <u>http://www.nejm.org/doi/full/10.1056/NEJMp1011024</u>

¹⁹ <u>http://vbhcglobalassessment.eiu.com/aneurin-bevan-university-health-board-wales-putting-value-based-care-into-practice/</u>

4. Role of HCIG - broader or more focused IEF

The revised IEF was presented to HCIG for discussion and approval in January 2018. As part of that presentation, the issues identified as part of the clinical engagement were resolved as follows:

- 1. COHORT: In the first instance it was discussed and agreed that the IEF should relate to the six funded community cardiology services, with an aspiration that in time the IEF would be applicable to all patients who are supported by community cardiology services
- 2. SAMPLING: It was determined that data from the whole cohort of patients that go through the funded community cardiology services would be provided and would feed the IEF
- QUANTITATIVE ↔ QUALITATIVE: The development of the transformation matrix and the inclusion of the accompanying narrative helped to redress the balance between the quantitative and qualitative measures within the IEF
- 4. TRANSACTIONAL ↔ TRANSFORMATIONAL: Similarly, the production of the transformation matrix helped to provide a better balance between the transactional and transformational aspects of the service
- 5. FREQUENCY: It was discussed and agreed that the three elements of the IEF should be completed annually as part of a return to WG, but that data could be collected and reported more frequently, especially if data systems could be automated to allow for this.

HCIG approved the IEF as described in Chapter 2 below.

2. THE ALL-WALES COMMUNITY CARDIOLOGY IMPACT EVALUATION FRAMEWORK

As described above, the All-Wales Community Cardiology Impact Evaluation Framework (IEF) is constituted of three elements:

1. Transformation matrix

The transformation matrix provides a framework for a qualitative assessment to be made of progress from more transactional to more transformational forms of community cardiology service delivery. The matrix is designed so that the services can determine which of the cells in the matrix best describes their progress to date against the 14 different dimensions within the three domains of service delivery, staff and value-based care. It is intended that the services could compare their progress over time from the more transactional to the more transformational parts of the matrix, and also to potentially compare their service with others in Wales. One of the benefits of the matrix is that services could use it to assess their progress in relatively short order – services would not need to engage in detailed data collection exercise to make an initial determination of progress against the matrix.

2. Core dataset

In addition to the matrix, detailed below is the core dataset for all community cardiology services in Wales. This provides a series of quantitative measures to complement the qualitative judgments made, and these measures are mapped to the Welsh Government's Key Objectives. The intention is that much of this data collection could become routine over time, but it is recognised that because the six different services have such different starting points this process of routinisation and standardisation will take time to complete. It is important also to note that the participation of NWIS in these processes is essential to gathering some of the more complex data items, like tracking patients to record their attendance at A&E for relevant cardiac related issues after their community cardiology appointments, or those with unplanned admissions related to cardiology.

3. Accompanying narrative

In order to link both of these two elements together, we suggest that a narrative is provided by the community cardiology services to explain the scores in the matrix and dataset. This narrative would be both retrospective and prospective, seeking to explain the judgements made in respect of the transformation matrix, and the data gathered as part of the core dataset.

As noted above, it is suggested that these three elements of the IEF are collected annually in a reporting process for Welsh Government, but it is possible that the elements could be collected more frequently for health boards to inform their local processes, especially if the analysis of elements of the core dataset collection could be systemised.²⁰

²⁰ Whilst not wishing to be overly prescriptive about the way in which the matrix should be used, it is important to note

Community Cardiology – Impact Evaluation Framework

Transformation matrix

Framework for a qualitative judgement which assesses progress from more transactional to more transformational forms of community cardiology service delivery.

Services can determine which of the cells in the matrix best describes their progress against 14 different dimensions across three domains.

Core dataset

Provides quantitative measures to complement the qualitative judgments made, all of which are mapped to the Welsh Government's Key Objectives for community cardiology services.

This core dataset is focused on one set of metrics that will be collected and reported by all community cardiology services in Wales, regardless of the form of their service provision.

Accompanying narrative

Linking narrative which brings the two previous elements together, and is provided by the community cardiology services to explain the scores in the matrix and dataset.

This narrative will take both a retro- and prospective approach to describing what has happened and why, as well as reflecting on future developments.

that it can be deployed variously within health boards. There should, of course, be one composite matrix that is completed at health board level in the return to Welsh Government, but this single matrix can be an amalgamation of a number of different matrices that have been completed by operational teams, managers, clinical directors and others either in combination or completing it alone. It is crucial though that having established a local approach, the same method is repeated the next time the matrix comes to be completed to ensure comparability over time. It is useful also to reflect on the purpose for completing the matrix – whether it is for reporting, for evaluation, or for learning. These are not mutually exclusive of course, but it is worth being clear for those completing the matrix as to the purpose.

COMMUNITY CARDIOLOGY - TRANSFORMATION MATRIX

Domoin	Descriptors – for each of the 14 dimensions below, which cell below best describes current progress?					
Domain	More transactional 🔸				More transformational	
1. SERVICE DELIVERY	1. SERVICE DELIVERY					
1.1 - Geographical location of service	In specialist secondary care centre	In DGH setting	In community hospital	In General Practice setting	In community setting	
1.2 - Location of specialist	In specialist secondary care, available for referral	In secondary care, immediate access for PwSI	In community hospital clinic	In General Practice setting	In community setting	
1.3 - Referrals ²¹	Triage from secondary care waiting list by consultant	Triage from secondary care waiting list by PwSI	Triage of current referral by consultant	Triage of current referral by PwSI	Direct referrals from primary care	
1.4 - Counterfactual [what would have happened if the CC service didn't exist?]	Limited data providing understanding what would have happened in lieu of CC service	Intermediate stage between limited data and 'good enough' data	'Good enough' data providing understanding what would have happened in lieu of CC	Intermediate stage between 'good enough' data and excellent data	Excellent data providing understanding on what would have happened in lieu of the CC service	
2. STAFF						
2.1 - Training and support of PwSI	Undertaking Bradford Diploma	Completed Bradford Diploma	Completed Bradford Dip., further training in sessions with cardiologist before starting to run clinics	Working in clinic with cardiologist available on site for mentoring	Working in clinic with cardiologist available remotely for mentoring	
2.2 - Responsibilities of specialist nurse	Clinical assessment only	Clinical assessment and test requests	Clinical assessment, test reporting	Clinical assessment, testing and prescribing	Full responsibilities of consultant nurse	
2.3 - Responsibilities of physiologist	Test only	Test and reporting	Test, triage, and risk assessment	Advanced clinical practice	Advanced clinical practice and prescribing	
2.4 - Responsibilities of clinical pharmacist	Medication optimisation without patient contact	Medication optimisation with patient contact	Simple prescribing	Advanced prescribing	Personal clinical lists and follow up	
2.5 - Redeployed capacity of staff	Limited data indicating the staffing impacts of the CC service	Intermediate stage between limited data and 'good enough' data	'Good enough' data indicating the staffing impacts of the CC service	Intermediate stage between 'good enough' data and excellent data	Excellent data indicating the staffing impacts of the CC service	
2.6 - Support and education for primary care	No support or education provided	Incorporated into standard educational programme	Education and support provided (teaching only)	Education and support provided (incorporating feedback)	Education and support provided (incorporating audit and feedback)	

²¹ These categories are not mutually exclusive, and in a more transformative model, referrals could come from a variety of sources. What will definitely change in the more transformational mode is the removal of the 'triage' function, as the service will be sustained by direct referrals from primary care.

Domain	Descriptors – for each of the 14 dimensions below, which cell below best describes current progress?				
	More transactional 🔸				More transformational
3. VALUE-BASED CARE					
3.1 - Patient-reported outcome measures (PROMs)	Limited/no collection of PROMs	Ad-hoc PROMs data collected	PROMs data collected from one defined sample of patients	PROMs data collected from multiple samples of patients and used to improve service delivery	Validated tool, routinely collected, reported on, and used to improve service delivery
3.2 - Patient-reported experience measures (PREMs)	Limited/no collection of PREMs	Ad-hoc PREMs data collected	PREMs data collected from one defined sample of patients	PREMs data collected from multiple samples of patients and used to improve service delivery	Validated tool, routinely collected, reported on, and used to improve service delivery
3.3 - Engagement in service development [initial and ongoing]	Team management	As previous, plus PwSI, GPs and Allied Health Professionals involved in service	As previous, plus cardiology consultants	As previous, plus cluster/locality clinical leads and managers	As previous, plus patient groups
3.4 - Pathways	Development of local pathway	Pilot, test and learn lessons about the local pathway	Development of health board pathway	Pilot, test and learn lessons about the health board pathway	Development of national/network pathway
TOTAL CELLS PER COLUMN Out of 14	n=	n=	n=	n=	n=

COMMUNITY CARDIOLOGY – CORE DATASET

CORE DATASET – RELEVANT TO COMMUNITY CARDIOLOGY SERVICES ACROSS WALES					
Domain	Data item	Relevant to which WG Key Objective?			
	Number of referrals to community cardiology clinic	2,4			
	Number of patients referred from existing waiting list (secondary care)	2,4			
	Number of new patients	2,4			
Referrals	Number of follow-up patients (e.g. patients previously seen in community cardiology clinic)	2,4			
	Number of patients referred directly by GP	2,4			
	Number of patients referred by other primary or community care clinician	2,4			
	Number of patients referred by secondary care clinician	1,3			
	Number of patients for whom the RTT pathway starts when the referral to secondary care is received	1,3			
Access	Referral to appointment time	3,4			
	Referral to treatment time	3,4			
	DNA rate	2			
	Number of patients who had a diagnostic test in the community cardiology clinic				
Diagnostics	 Echocardiogram ECG monitoring CHADs2-VASC HASBLED Other diagnostic test 	1			
Outcome of community clinic appointment – diagnosis	 Number of patients diagnosed at community cardiology clinic Atrial fibrillation Documented arrhythmia Non-pathological palpitations Systolic heart failure Other form of heart failure Cardiac disease Other cardiac cause 	1,3			
	Number of patients with confirmed non-cardiac cause	1,3			
	Number of patients with no cause found	1.3			

CORE DATASET – RELEVANT TO COMMUNITY CARDIOLOGY SERVICES ACROSS WALES					
Domain	Data item	Relevant to which WG Key Objective?			
	Number of patients given advice only	1,3,4			
	Number of patients recommended to initiate anticoagulation	1,3,4			
Outcome of	Number of patients recommended to initiate ACEi/ARB	1,3,4			
community	Number of patients recommended to initiate b-blocker	1,3,4			
clinic appointment	Number of patients recommended to initiate MRA	1,3,4			
- treatment/	Number of patients recommended to initiate other medication	1,3,4			
Intervention	Number of patients titrated to optimal dose of existing medication	1,3,4			
	Number of patients recommended rate control	1,3,4			
	Number of patients recommended rhythm control	1,3,4			
	Number of patients discharged from community cardiology clinic with no onward referral	1,3,4			
0.1	Number of patients referred to cardiology consultant in secondary care	1,3,4			
community	Number of patients referred to specialist nurse	1,3,4			
clinic appointment	Number of patients referred to cardiac rehabilitation	1,3,4			
– referral	Number of patients referred to other speciality	1,3,4			
	Number of patients referred for urgent investigation	1,3,4			
	Number of patients admitted to hospital	1,3,4			
	Numbers PROMs/PREMs	1,6			
Patient reported outcomes	Patient satisfaction e.g. travel, parking, satisfaction with appointment in community	1,6			
	EQ-5D scores before and after appointment/intervention ²²	1,6			
Admissions	Number of patients attending A&E for relevant cardiac related issues within 6 months of community cardiology appointment (patients attending for a new or different event should not be included)	5			
admissions to hospital [Role for	Number of patients with unplanned admission within 6 months of community cardiology appointment (or reduction in all unscheduled admissions)	5			
NWIS]	Number of patients referred to secondary care cardiology within 6 months of community cardiology appointment	5			

 $^{^{\}rm 22}$ An explanation of the EQ-5D questionnaire is provided in the Appendix below.

CORE DATASET – RELEVANT TO COMMUNITY CARDIOLOGY SERVICES ACROSS WALES				
Domain	Data item	Relevant to which WG Key Objective?		
	Total number of patients that could be seen in community clinics at full capacity (total gross annual capacity)	6		
Cost and	Total number of patients booked into community clinics (annual)	6		
utility	Total number of patients attending community clinic appointment (annual)	6		
	Total annual cost of community service	6		

3. CONCLUSION

This paper marks the end of the design phase of the IEF, and the responsibility for the implementation of the IEF now rests with a number of key partners: HCIG, the All-Wales Cardiac Network, the health boards and the British Heart Foundation. It is not within the gift of this study to dictate the next steps, but the following seem sensible in taking the intellectual content of this paper into the reality of service delivery – that:

- A set of documents need to be produced in the relevant formats based on the elements of the IEF as described above in order to ensure that they can be used for data collection purposes;
- Alignment between the data collection pro forma and the data analysis functions needs to be achieved so that all of the stakeholders can feel confident in the impact assessments that they are making;
- Building on the issues raised earlier in this paper, clear guidance, guidelines and instruction need to be issued in respect of timelines and expectations of data collection and analysis; and
- Involving NWIS as the IEF is implemented is crucial to ensure that these processes become routine and are standardised effectively.

APPENDIX – Background to the EQ-5D questionnaire

The EQ-5D is a Health-Related Quality of Life (HRQoL) questionnaire that captures patient-reported outcomes in two ways. Firstly, patients are asked to report their assessment of their health state on five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression at five levels ranging from 'no problems' to 'severe problems'. These patient responses generate a five-figure profile that is converted to an individual utility score that represents that person's current HRQoL which can also be used for health economic evaluation to enable estimation of quality adjusted life years (QALYs). The resulting EQ-5D utility scores range from perfect health to worst possible health. A Visual Analogue Scale (VAS) is also included in this questionnaire, which is a thermometer-type scale that requires a self-rated valuation of the health state experienced by the respondent on a scale of 0 to 100. The utility scores are derived from a survey of the general public and represent a preference based valuation of a health state characterised by the EQ-5D. The VAS score however is a self-rated valuation and represents the respondent view of their health state and how it affected their life on the day. A copy of the questionnaire is provided below.

Various validation studies of the EQ-5D have been carried out for patients with a range of conditions.²³ This generic questionnaire can be administered in a variety of ways, on paper as a self-completed survey or interviewer administered. It is quick and easy to complete (reduced patient burden) and is NICE's (National Institute for Health and Care Excellence) preferred method of gathering HRQoL data for economic evaluations (cost effectiveness and cost utility analyses, using QALYs). NICE has outlined their preferred method of assessing HRQoL for economic evaluations, and confirms its validity on a range of patient populations. Essentially, this instrument enables 'before' and 'after' comparisons for health-related interventions (services, treatments, etc.) to be made and also enables the NHS and NICE to make comparisons of cost effectiveness and HRQoL differences within and between a wide range of health conditions.²⁴

²³ Longworth L, Yang Y, Young T, et al (2014) 'Use of generic and condition-specific measures of health-related quality of life in NICE decision-making: a systematic review, statistical modelling and survey' *Health Technology Assessment*, 18.9, NIHR Journals Library: Southampton (see: <u>http://www.ncbi.nlm.nih.gov/books/NBK261619/</u>)

²⁴ See *Guide to the Methods of Technology Appraisal* (2013): <u>https://www.nice.org.uk/article/pmg9/chapter/the-reference-case#framework-for-estimating-clinical-and-cost-effectiveness</u>

EQ-5D Questionnaire

Under each heading, please tick the ONE box that best describes your health TODAY

MOBILITY

I have no problems in walking about	
I have slight problems in walking about	
I have moderate problems in walking about	
I have severe problems in walking about	
I am unable to walk about	

SELF-CARE

I have no problems washing or dressing myself	
I have slight problems washing or dressing myself	
I have moderate problems washing or dressing myself	
I have severe problems washing or dressing myself	
I am unable to wash or dress myself	

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

I have no problems doing my usual activities	
I have slight problems doing my usual activities	
I have moderate problems doing my usual activities	
I have severe problems doing my usual activities	
I am unable to do my usual activities	

PAIN / DISCOMFORT

ANXIETY / DEPRESSION

I am not anxious or depressed	
I am slightly anxious or depressed	
l am moderately anxious or depressed	
I am severely anxious or depressed	
l am extremely anxious or depressed	

EQ-5D Visual Analogue Scale (VAS)

The best health you can imagine

We would like to know how good or bad your health is TODAY. This scale is numbered from 0 to 100.

- 100 means the <u>best</u> health you can imagine.
 0 means the <u>worst</u> health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =



you can imagine



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