



UNIVERSITY OF  
BIRMINGHAM



CENTRE FOR PATIENT REPORTED OUTCOMES RESEARCH

# PROMS Research Conference Programme

University of Birmingham  
20th June 2018

Hosted by the Centre for Patient Reported Outcomes Research



# PROGRAMME OVERVIEW

## Wednesday 20th June

- 09:30 Registration and Refreshments  
10:00 Welcome  
Professor Melanie Calvert and Gary Price

## Plenary Session 1

- 10:15 Dr Tessa Richards, BMJ  
Cancer from the patients perspective  
Dr Dan O'Connor, MHRA  
PROs from the regulatory perspective

## Parallel Session 1

- 10:45 Move to parallel sessions

<b>Great Hall</b> Minimising PRO waste	<b>WG05</b> PROs in chronic disease/ different settings	<b>WG12</b> Cutting edge methods
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- 11:45 Poster Viewing and Refreshments in the Great Hall

## Parallel Session 2

- 12:00 Move to parallel session

<b>Great Hall</b> Pushing boundaries	<b>WG05</b> Economic evaluation	<b>WG12</b> Digital Capture of PROs
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- 13:00 Lunch and Poster Viewing in Great Hall

## Parallel Session 3

- 14:00 Move to parallel session

<b>Great Hall</b> Digital Capture of PROs	<b>WG05</b> PROs in chronic disease/ different settings	<b>WG12</b> Cutting edge methods
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- 15:00 Poster Viewing and Refreshments in the Great Hall

## Plenary Session 2

- 15:30 Dr Kirstie Haywood, University of Warwick  
'Working together to improve outcomes research': how innovations from patient and public involvement (PPI) research can inform the future of patient-reported outcomes (PRO) and health-related quality of life (HRQoL) research.  
16:00 General discussion  
16:30 Close

# PARALLEL SESSION DETAILS

## Session 1: Minimising PRO waste

Room: Great Hall

Chair: Melanie Calvert

10:50	<b>Alexis Foster</b>	Identifying the facilitators and barriers to implementing Patient Reported Outcome Measures: A systematic review of reviews
11:00	<b>Kerry Avery</b>	Development of a core outcome set capturing key concepts relevant to safe and efficient evaluation of innovative invasive procedures
11:10	<b>Lien Dorme</b>	Current State of Statistical Analysis of Patient Reported Outcomes Data in Cancer Randomized Controlled Trials on Locally Advanced and Metastatic Breast Cancer – A Systematic Review
11:20	<b>Jenny Harris</b>	Handling missing PROs for multivariate models: a practical guide to multiple imputation using chained equations
11:30	<b>Discussion</b>	

## Session 1: PROs in chronic disease/different settings

Room: WG05

Chair: Elizabeth Gibbons

10:50	<b>Grace Turner</b>	A survey of Patient Reported Outcome Measures (PROMs) used in General Practice in England
11:00	<b>Gurpreet Jutley</b>	Fatigue in patients with newly presenting inflammatory arthritis and inflammatory arthralgia
11:10	<b>Roanna Burgess</b>	Models used for risk-adjustment of health outcomes in musculoskeletal services: A systematic review of the literature.
11:20	<b>Michelle Holmes</b>	Patient-reported outcome measures (PROMs) in clinical practice for non-malignant pain: a realist review and theoretical framework
11:30	<b>Discussion</b>	

## Session 1: Cutting edge methods

Room: WG12

Chair: Caroline Potter

10:50	<b>Edward Webb</b>	A novel way of anchoring discrete choice experiments valuing EQ-5D
11:00	<b>Francesca Torelli</b>	The "cost" of care for the elderly: differential health status in adult carers and non-carers
11:10	<b>Tim Benson</b>	Four short measures for evaluating digital health innovation
11:20	<b>Samantha Cruz</b>	Assessing the impact of patient-reported outcome (PRO) data from clinical trials: a systematic review
11:30	<b>Discussion</b>	

## Session 2: Pushing boundaries

Room: Great Hall

Chair: Magdalena Skrybant

- 12:05 **Grace Turner** Embedding patient and public involvement within the Centre for Patient Reported Outcomes Research
- 12:15 **Andrew Grundy** A critical assessment of service user involvement in co-producing a new self-reported mental health outcome measure of Recovering Quality of Life (ReQoL) A critical assessment of service user involvement in co-producing a new self-reported mental health outcome measure of Recovering Quality of Life (ReQoL)
- 12:25 **Steven Blackburn** An innovative framework for embedding meaningful Patient and Public Involvement in PROMS development
- 12:35 **Nathan Pearson** Co-constructing a new Axial Spondyloarthritis (axSpA) specific measure of energy and fatigue: a researcher's reflection on patient involvement
- 12:45 **Discussion**

## Session 2: Economic evaluation

Room: WG05

Chair: John Brazier

- 12:05 **Hannah Penton** Considerations in conducting economic evaluations in health and social care services in elderly populations: An investigation of the measurement performance of the EQ-5D-5L, SF-12, ASCOT and WEMWBS in older people using item response theory and differential item functioning
- 12:15 **Charlotte E Kosmas** Time Trade-Off (TTO) – Does there need to be clarity on how health state descriptions are developed and the task administered?
- 12:25 **Koonal Shah** Valuing the EQ-5D-Y Using a Discrete Choice Experiment: Do Adult and Adolescent Preferences Differ?
- 12:35 **Cara Bailey** "We measure differently now": a feasibility study exploring how hospice patient's value attributes of the ICECAP-SCM for use in economic evaluation at end of life.
- 12:45 **Discussion**

## Session 2: Digital Capture of PROs

Room: WG12

Chair: Derek Kyte

- 12:05 **Galina Velikova** eRAPID: electronic patient self-Reporting of Adverse-events: Patient Information and aDvice. Patient recruitment and retention in pilot and randomised studies in oncology
- 12:15 **Kerry Avery** Feasibility of digital self-report PRO data for monitoring adverse events after discharge following major abdominal cancer surgery: the eRAPID study
- 12:25 **Pushpendra Goswami** Assessment of measurement equivalence of the paper-based and electronic version of a newly developed haematology specific patient-reported outcome measure, HM-PRO
- 12:35 **Paul Wicks** Thrive - Online Development of a Positive and Patient-Centric PROM to Support Self-Management and Biomedical Discovery on PatientsLikeMe
- 12:45 **Discussion**

### Session 3: Digital Capture of PROs

Room: Great Hall

Chair: Mauro Lencioni

14:05	<b>Alice Bellchambers</b>	Do patients engage with an online patient reported outcome measure (PROM), post-shoulder surgery, and what factors influence their engagement?
14:15	<b>Derek Kyte</b>	The use of an electronic Patient-Reported Outcome Measure in the Management of Patients with Advanced Chronic Kidney Disease: The RePROM Pilot Trial
14:25	<b>Anita Slade</b>	Increasing capture of patient-reported outcomes in trauma research
14:35	<b>Olalekan Lee Aiyegbusi</b>	A qualitative study of patients' and clinicians' perspectives on the use of electronic Patient-Reported Outcome measures (ePROMs) in the management of patients with Advanced Chronic Kidney Disease (PRO-track Project)
14:45	<b>Discussion</b>	

### Session 3: PROs in chronic disease/different settings

Room: WG05

Chair: Jose M Valderas

14:05	<b>Agnes Williams</b>	How do alcohol-dependent individuals, who repeatedly present to A&Es, engage with structured questionnaires? A mixed methods study
14:15	<b>Amanda Cole</b>	What Outcomes Matter in Cancer? A Literature Review
14:25	<b>Belene Podmore</b>	Comorbidity in patient-report and administrative data varied in agreement in a cohort of joint replacement patients
14:35	<b>Anne Marie Russell</b>	Challenges of developing and testing a condition-specific Patient Reported Outcome Measure in a rare condition - Idiopathic Pulmonary Fibrosis (IPF-PRO Study)
14:45	<b>Discussion</b>	

### Session 3: Cutting edge methods

Room: WG12

Chair: Alastair Denniston

14:05	<b>Carol McLoughlin</b>	What outcome measures should we use with informal carers? An analysis of the validity of 5 different measures across 4 conditions
14:15	<b>Mike Horton</b>	Development of a Quality of Life Instrument for Dementia Carers
14:25	<b>Esther Kwong</b>	Feasibility of collecting and assessing patient-reported outcomes for emergency admissions: laparotomy for gastrointestinal conditions
14:35	<b>Hollie Richards</b>	Digital PRO data collection is a beneficial adjunct to patient self-management during recovery following major abdominal cancer surgery: the eRAPID study.
14:45	<b>Discussion</b>	

# POSTER PRESENTATIONS

Poster	Presenting Author	Abstract Title
01	<b>John O'Dwyer</b>	Valuing health - who cares?
04	<b>Olalekan Lee Aiyegbusi</b>	Development and usability testing of a web-based electronic patient-reported outcome measure (ePROM) system for patients with advanced chronic kidney disease
07	<b>Anita Slade</b>	Living with a Left Ventricular Assist Device: Patient-Partner Perspectives
09	<b>Rasmus Blechingberg Friis</b>	Intensifying lung cancer surveillance - The development of a web-based Patient Reported Outcome application for a multicenter randomized trial in Denmark
11	<b>Helen Twohig</b>	Development of a patient reported outcome measure for polymyalgia rheumatica
14	<b>Laurie Batchelder</b>	Further structural validation of the Long-Term Conditions Questionnaire (LTCQ): Formation of the Rasch 8-item LTCQ short-form (LTCQ-8)
16	<b>Bethan Copsey</b>	Variation and poor reporting on the measurement of patient-reported outcomes can hinder the interpretation of study findings: a case study using the WOMAC measure
17	<b>Nashmel Sargalo</b>	Predictors of Quality of Life (QoL) in People with Epilepsy in the UK and Kurdistan
18	<b>Samantha Mason</b>	Evaluating Patient Reported Outcome Measures (PROMs) for bladder cancer: a systematic review using the COSMIN checklist.
19	<b>Hareth Al-Janabi</b>	How does patient care affect family carers' outcomes? A qualitative study in dementia, mental health and stroke
20	<b>Ishpal Moonga</b>	Quality of life in long term survivors of High Grade Gliomas – a PROMS study
22	<b>Rabab Abdulhamid</b>	Validity and reliability of Arabic MOS social support survey.
23	<b>Duncan Short</b>	Can patient-reported measures and outcomes (PROs) improve routine HIV consultations? A targeted review of the literature.
24	<b>Anita Slade</b>	Is the Rivermead Mobility Index a suitable measure for people living with MS in the community?

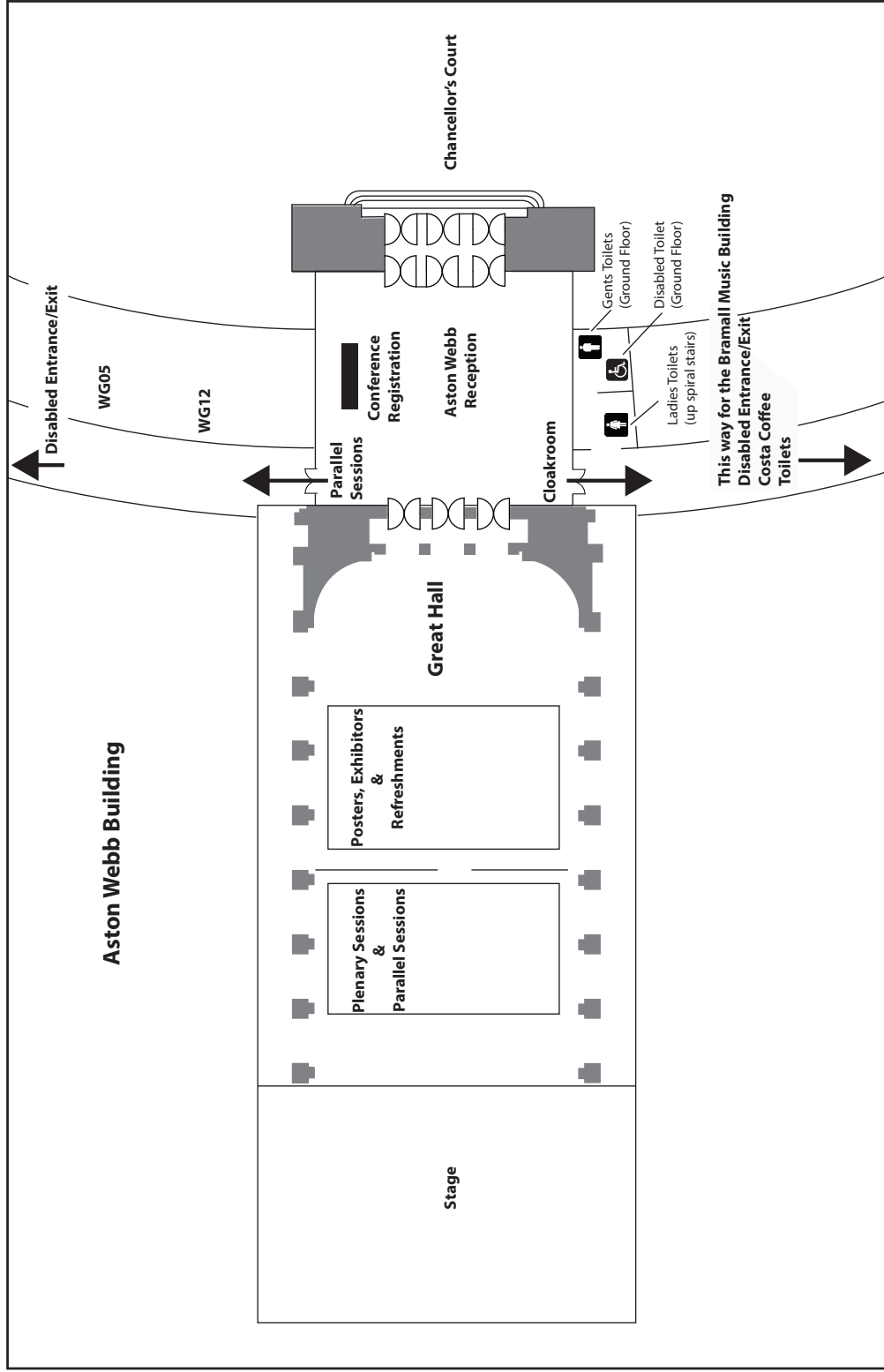
Poster	Presenting Author	Abstract Title
26	<b>Alex Theobald</b>	How useful is the Musculoskeletal Health Questionnaire (MSK-HQ) to demonstrate health outcomes in chronic pain patients who successfully completed a cognitive behavioural and exercise intervention?
30	<b>Jeremy Rodrigues</b>	Site-specific patient-reported outcome measures for hand conditions: a systematic review of their development and psychometric properties
34	<b>Jill Carlton</b>	Paper versus online: data collection methods affect the sociodemographic and health profile of the sample
35	<b>Jill Carlton</b>	Validation of the Health and Self-management in Diabetes (HASMID) patient reported outcome measure (PROM)
36	<b>Clara Mukuria</b>	THE E-QALY PROJECT: DEVELOPING CONTENT FOR A NEW GENERIC MEASURE - RESULTS FROM A QUALITATIVE LITERATURE REVIEW
39	<b>Philip Powell</b>	Measuring quality of life in people with Duchenne Muscular Dystrophy: developing a new patient reported outcome measure
40	<b>John Brazier</b>	EXTENDING THE QALY (E-QALY) PROJECT: STAGES FOR DEVELOPING A NEW GENERIC MEASURE
42	<b>Derek Kyte</b>	Systematic evaluation of patient-reported outcome (PRO) protocol content and reporting in cancer clinical trials: the EPIC study
43	<b>Birgith Grove</b>	Tele follow-up using Patient-reported Outcomes (PRO) measures in patients with chronic kidney disease - the PRO-KID study: A study protocol for a non-inferiority randomised controlled trial in Denmark
48	<b>Patricia Holch</b>	Cancer awareness, risk perception and barriers to help seeking in teenage and young adults (TYA)
49	<b>Antoinette Davey</b>	Exploring the variation of patient-reported outcome scores across different time-points (day, week, month) for patients with multiple conditions: Protocol for a longitudinal qualitative analysis

Poster	Presenting Author	Abstract Title
52	<b>Jenny Harris</b>	What are the predictive risk factors for anxiety after treatment for breast cancer and how are existing multivariate models developed? A systematic review
53	<b>Sally Appleyard</b>	Barriers to remote electronic completion of Quality of Life Patient reported outcome measures: qualitative results from a feasibility study in men with advanced prostate cancer.
55	<b>Jane Wells</b>	At-home completion to support the evaluation of content validity, usability, feasibility and preliminary measurement properties of electronic patient-reported outcome measures (ePROMs)
56	<b>Krister Cromm</b>	Measuring treatment related Quality of Life in Lipoprotein Apheresis Patients
57	<b>Mark Larkin</b>	REAL-WORLD HRQL IN PATIENTS WITH MELANOMA DERIVED USING A DIGITAL 'BRING YOUR OWN DEVICE' PLATFORM
59	<b>János Valery Gyuricza</b>	Psychosocial Consequences of Labelling Mild Hypertension: Development of a condition-specific Patient Reported Outcome Measure (PROM)
60	<b>Rhiannon Macefield</b>	The Selfi wound study: Exploring the feasibility of collecting patient self-taken images of primary surgical wounds after leaving hospital, for remote and blinded outcome assessment of surgical site infection
62	<b>Lorraine Warrington</b>	Systematic review of online systems for patients to report and manage side effects of cancer treatment
67	<b>Romualdo Ramos</b>	Development of an Adaptive Assessment Tool of Occupational Balance for Chronic Care Management: A Salutogenic Approach
69	<b>Angela Rylands</b>	Key considerations for the collection of patient centred data in the real world



Poster	Presenting Author	Abstract Title
70	<b>Caroline Potter</b>	Efficient PROM development? Adaptation of the Long-Term Conditions Questionnaire (LTCQ) for use with carers of dementia patients
76	<b>Tim Benson</b>	A Survey of Carers and Cared For
77	<b>Tim Benson</b>	Care Home Staff Perception of Work Wellbeing, Job Confidence and Service-Provided
78	<b>Emma Lidington</b>	The young adult cancer patient (25-39 years) experience: A qualitative study looking at the needs and challenges of an underserved population
79	<b>Tim Benson</b>	Using PROMs and PREMs in the Evaluation of New Care Models in North East Hampshire and Farnham Vanguard

# FLOOR PLAN



# Edgbaston Campus mobility map

## Index to buildings by zone



### Red Zone

- R1 Law Building
- R2 Frankland Building
- R3 Hills Building
- R4 Aston Webb – Lapworth Museum
- R5 Aston Webb – B Block
- R6 Aston Webb – Great Hall
- R7 Aston Webb – Student Hub
- R8 Physics West
- R9 Nurfield
- R10 Physics East
- R11 Medical Physics
- R12 Biomedical Music Building
- R13 Printing Building
- R14 Barber Institute of Fine Arts
- R15 Watson Building
- R16 Arts Building
- R17 Ashley Building
- R18 Stratheona Building
- R19 Education Building
- R20 J G Smith Building
- R21 Murhead Tower
- R22 University Centre
- R24 Staff House
- R26 Geography
- R27 Biosciences Building
- R28 Murray Learning Centre
- R29 The Alan Walters Building
- R30 Main Library
- R31 Collaborative Teaching Laboratory
- in development

### Blue Zone

- B1 Medical School
- B2 Institute of Biomedical Research including IBR West
- B3 Wellcome Clinical Research Facility
- B4 Robert Aitken Institute for Clinical Research
- B5 CRUK Institutes for Cancer Studies and Denis Howell Building
- B6 Research Park
- B7 90 Vincent Drive
- B8 Henry Wellcome Building for Biomedical NMR Spectroscopy
- B9 Medical Practice and Dental Centre
- B10 Advanced Therapies Facility
- B11 BioHub Birmingham
- B12 Health Sciences Research Centre (HSRC)

### Orange Zone

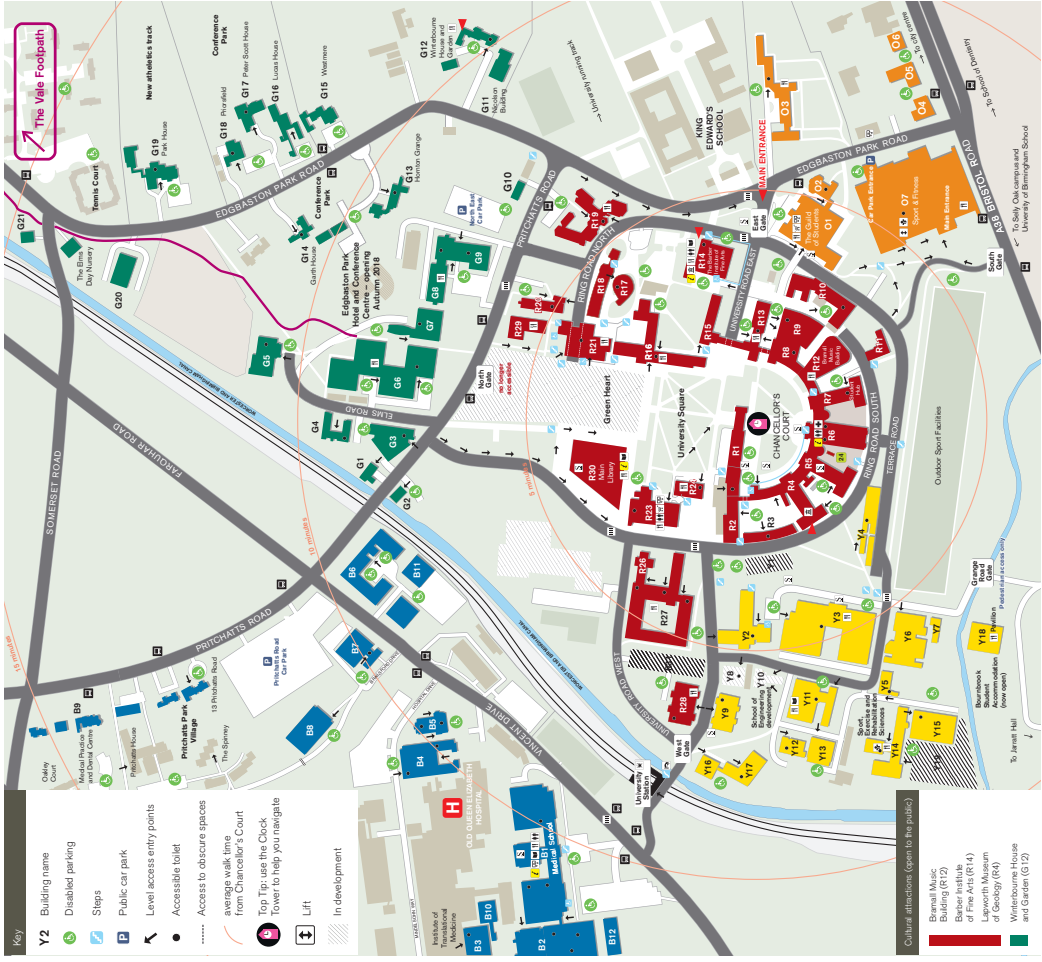
- O1 The Guild of Students
- O2 St Francis Hall
- O3 University House
- O4 Ash House
- O5 Beech House
- O6 Cedar House
- O7 Sport & Fitness

### Green Zone

- G1 32 Pritchatts Road
- G2 31 Pritchatts Road
- G3 European Research Institute
- G4 3 Elms Road
- G5 Computer Centre
- G6 Metallurgy and Materials
- G7 IRC Net Shape Laboratory
- G8 Gisbert Kapp Building
- G9 52 Pritchatts Road
- G10 54 Pritchatts Road
- G11 Nicolson Building
- G12 Winterbourne House and Garden
- G15 Westmere
- G18 Priorsfield
- G19 Park House
- G20 Elms Plant
- G22 Elms Day Nursery
- Green Zone Conference Park
- G13 Honton Grange
- G14 Garth House
- G16 Lucas House
- G17 Peter Scott House

### Yellow Zone

- Y1 Old Gymnasium – in development
- Y2 Havorth Building
- Y3 Mechanical and Civil Engineering Building
- Y4 Terrace Huts
- Y5 Estates West
- Y6 Maintenance Building
- Y7 Grounds and Gardens
- Y8 Chemistry West
- Y9 Computer Science
- Y10 Alta Bioscience
- Y11 Chemical Engineering
- Y12 Biochemical Engineering
- Y13 Chemical Engineering Workshop
- Y14 Sport, Exercise and Rehabilitation Sciences
- Y15 Civil Engineering Laboratories
- Y16 Occupational Health
- Y17 Public Health
- Y18 Bournebrook Student Accommodation
- Y19 Bournebrook Student Accommodation



- Key**
- Y2 Building name
  - Disabled parking
  - Steps
  - Public car park
  - Level access entry points
  - Accessible toilet
  - Access to outdoor spaces
  - average walk time from Chancellor's Court
  - Top Ten: use the Clock Tower to help you navigate
  - Lift
  - in development

- Cultural attractions (open to the public)**
- Barndale Music Building (R12)
  - Barber Institute of Fine Arts (R14)
  - Wellcome Centre for Integrative Systems of Genealogy (R4)
  - Winterbourne House and Garden (G12)