

2018 iCAN RESEARCH & ADVOCACY SUMMIT



July 8-13
#iCANSummit2018



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Welcome and Remarks

We are delighted to welcome you to the annual summit for The International Children's Advisory Network (iCAN).

Now in our fourth year, we bring together over 140 delegates across the United Kingdom, United States, Europe, academia, and industry to explore, to learn, and to speak about our mission: **to foster greater global understanding about the importance of the paediatric patient and caregiver voice in healthcare, clinical trials, and research.**



On behalf of the International Children's Advisory Network Executive Steering Committee, welcome to Edinburgh, Scotland, and to the 2018 iCAN Research & Advocacy Summit. Over the course of the week, you will have the opportunity to interact with 65 youth advisors from 9 countries from 2 continents, all united behind a common purpose to provide children and families a global voice in health, medicine, research, and innovation. I'd like to extend a special thank you to Pamela Dicks, the ScotCRN team, and the Summit Planning Committee for their tireless efforts to put together this incredible meeting. You will learn from some of the world's leading paediatric innovators and researchers, have ample opportunity to let your voices be heard, continue to chart the course for iCAN's future, and, of course enjoy the beautiful city of Edinburgh. Thank you for joining us this week!

Charlie Thompson, MD, FAAP
Chairman and Founder, iCAN Research



Welcome to the exceptional opportunity to interact with youths who have cultivated their voices and knowledge base around healthcare, research, and advocacy. As a young person, I was fortunate to hear that you are never too young to learn! I remember being excited to hear about complex topics, and this conference reminds me that eager minds paired with infrastructure create unbeatable synergy for youth advisors and adults who want to interact on shared projects. Today's youths communicate and participate in their communities at lightning speed, and we remain so excited to support and provide information for them to consider and use as they make decisions and advocate for themselves in health and life scenarios. Administration congratulates each team, team leader, and sponsor on their choice to join us this week. We look forward to what we will do together.

Laura McMaster, LMFT, CCRP
Director, iCAN Research

Summit Overview

We are delighted to offer you this unique programme for the Scottish iCAN Summit. The annual iCAN Research and Advocacy Summit brings together youth advisors, parents, local team leaders, academics, paediatricians and industry sponsors. There are exciting and inspirational workshops all related to clinical research, youth advocacy and future medicines. Many of the presentations are from experts in children's medicines and healthcare or from our own youth members. There is a clinical trial challenge, running throughout the week which will be linked to plenary sessions and workshops – resulting in the youth members designing in teams their own clinical trials. On Friday we have a change of venue and a move to biotechnology for children's healthcare and innovations.

We ask you to come with an open mind, participate fully, meet new friends and discover what young people can actually do to improve the patient acceptability of drug trials and healthcare innovations.

Please use this guide to help make the most of your day.

If you require any assistance please contact event staff at the registration desk in the foyer or a member of the iCAN team.

Pamela Dicks
Paediatrics Network Manager
NHS Research Scotland

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We are delighted to host the 2018 summit at the University of Edinburgh, John McIntyre Conference Centre, Southhall Centre and at Dynamic Earth. Please note there is free parking at the JMCC and Southhall. Please let us know if you require parking at Dynamic Earth.



John McIntyre Conference Centre



Dynamic Earth

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Filming and Photography will be captured and may be used at the event, on the website or in future iCAN conference event materials. Any delegate not wishing to be photographed or filmed please inform staff at registration if you have not already done so.

Wi-Fi access details

Look for the **Keysurf** network:

- Register once with email address and contact number
- Once registered, you will automatically be logged onto the network in JMCC & Southhall.

If you require any assistance please call Pamela Dicks on +44 07964913011.

Programme Outline

Sunday July 8

Southhall Pollock Halls

Welcome and Orientations

15:00 - 16:00	Registration and Welcome Desk Open
15:00 - 16:00	Pod Facilitators Meet/Greet
16:00 - 17:00	Leadership Breakout
16:00 - 17:00	Youth Pod Leader Meet/Greet
17:00 - 18:30	Speed Presentations
18:30 - 17:00	Welcome BBQ

Monday July 9

Plenary

09:00 - 09:05	Summit Welcome Charlie Thompson ICAN Chair	
09:05 - 09:30	Opening Address Maureen Watt, Member Scottish Parliament – Minister for Mental Health	
09:30 - 10:00	How Drug Development Changed Outcomes for Respiratory Disease Professor Steve Cunningham	
10:00 - 11:00	Clinical Trial Design Dr Alun Hughes	
11:00 - 11:30	Coffee/Tea Break	
	<u>Youth Workshops</u>	
11:30 - 12:30	Designing Patient Information Sheets (Jennifer Preston), Formulations (Prof Matthew Peake, Dr Louise Bracken, Jennifer Duncan, Emma McDonough), Clinical Trial Design (Dr Alun Hughes)	Salisbury, Pentland West, and Holyrood
12:30 - 13:30	Catered Lunch	Restaurant Self Service
13:30 - 15:30	Swap workshops x2	Salisbury, Pentland West, and Holyrood
15:30 - 17:00	Drug Discovery Challenge: Write Your Protocols!	Salisbury, Pentland West, and Holyrood

**17:00 -
Evening**

Free Time

Parent and Facilitator Workshops

11:30 - 12:30	Future Leadership Directions Leanne West, Christine Woods, and Laura McMaster	Pentland East
12:30 - 13:30	Catered Lunch	Restaurant Self Service
13:30 - 15:30	Social Media: Using Twitter to Promote iCAN, your chapter, and projects. Keeping vulnerable members safe Simon Cree & Simon Stones	Pentland East
15:30 - 17:00	Business Meeting: Parents and Facilitators	Pentland East

Tuesday July 10
Southhall Pollock Halls

Educational and Rare Disease Day

Plenary

09:30 - 10:00	What is a rare disease, and how do we use international registries/networks to improve healthcare for children with rare diseases? Dr Martina Rodie	Southhall
10:00 - 10:45	Ethics of Doing Research with Children Dr Bob Phillips	Southhall
10:45 - 11:00	Coffee/Tea Break	
11:00 - 11:30	Why Fit in When You Were Born to Stand Out? Benjamin James and Simon Stones	Southhall
11:30 - 11:45	When medicines change lives – my experience with JIA and transitioning to University Anna Sherriffs	Southhall
11:45 – 12:00	A Parent's Perspective: Frankie's Journey with Dravet's Stacey Hutchison	Southhall
12:00 - 12:15	Advocating for Children with Type 1 Diabetes in the US Reece and Olivia Ohmer	Southhall
12.15 - 12.45	Panel QA	
12:45 - 13:45	Catered Lunch	Kirkland

Youth Workshops

13:45 - 14:30	<ol style="list-style-type: none"> 1. Drug Discovery Challenge: Dr Alun Hughes 2. Can you imagine a word without antibiotics? Dr Nicholas Brown, Dr Enas Newire 3. Ethics: Dr Bob Phillips 	VIP/Foyer Southhall Kirkland
14:30 - 16:30	Swap Workshops x2	As above
16:30 - 17:30	Designing a Project from Concept to Delivery for 16plus YP Dr. Sharon Smith	Southhall

Parent and Facilitators Workshops

13:45 - 14:30	Digital Patient Records Christine Woods	Absorb
14:30 - 16:30	How to Develop, Run, and Manage an iCAN Chapter Begonya Escalera, Segolene Gaillard	Absorb
16:30 - 17:30	The Role of a Research Nurse: the patient's advocate Susan MacFarlane and Liz Waxman	Absorb
19:00	Meal Out and Ghost/Horrible Histories Tour of Old Edinburgh	

Wednesday July 11 **Southhall Pollock Halls**

Improving Health and Quality of Life

Plenary

09:30 - 10:15	Improving Health and Quality of Life with Singing Professor Graeme Wilson	Southhall
10:15 - 10:35	The individual's journey within the music therapy process "See me, hear me, listen to me." Brian Smith	Southhall
10:35 - 11:05	Determinants of a Child's Health Vivian Tsang	Southhall
11:05 - 11:20	Coffee/Tea Break	
11:20 - 11:50	Genetic Testing - to know or not to know? Jessica Lorimer, Saskia Oosterveld, Oliver Tailby	Southhall
11.50 - 12:45	Youth Perspective on Living with a Rare Condition Living and Advocating with an Invisible Illness Sophie Ainsworth When You Wake Up after a Nightmare Marta Botanch	Southhall

An Uncommon Life with an Uncommon Condition
Hampton Woods

12:45 - 14:00 Working Lunch: Pods

14:00 - Evening Free time – explore Edinburgh

Thursday 12 July
Southhall Pollock Halls

iCAN Young Informers

Plenary

09:00 - 09:30 #datasaveslives
Steph Wright

09:30 - 10:00 Learning what the risks from new medicines could be: how patients can help
Dr Dan Hawcutt

10:00 - 10:30 Who does what? Industry, Contract research organisations and the regulator
Claudio Fracasso, Cindy Jackson, Dr Angeliki Siapkara

10:30 - 10:45 A Career in Drug Development?
Dr Sue Tansey

10:45 - 11:00 Coffee/Tea Break

11:00 - 13:00 Workshops and Seminars in groups see table below

13:00 - 14:00 Catered Lunch

14:00 - 17:30 Workshops Continued

17:30 - Evening Fish and Chips and Mini-Highland Games

Friday July 13
Dynamic Earth

Technology The Future of Medicine

08:30 Leave Accommodation, Venue Change

09:30 - 11.30 Drug Discovery Challenge - Presentations

- 11.30 - 12.00** **Technology for Sharing Patient Generated Data: friend or foe?**
Elin Haf Davies
- 12.00 - 12.30** **Technology and Devices for Children's Health**
Paul Dimitris
- 12.30 - 13.00** **Catered Lunch**
- 13.00 - 15.30** **Technology Exhibition Sessions**
- Technology Innovation Transforming Child Health**
Tookie
Pneumacare
Child Prosthetics, Limb Power and Open Bionics
Strathclyde University
- 15.30 - 17.00** **Optional Tour Dynamic Earth**

Thursday 12 Workshops

Colour Code	Group 1 CYP	Group 2 CYP	Facilitators, parents and supporters	
Room	Southhall	Kirkland	Absorb	VIP
Time				
11.00-11.45	Pfizer	El Lilly	PRA	
11.45-12.30	PRA	Yellow Card Scheme	IQVIA	
12.30-13.00	Premier	Synteract	Pfizer	
13.00-14.00	LUNCH			
14.00-14.30	Synteract	Premier	Yellow Card Scheme	
14.30-15.15	COMET (Univ Liv)	Pfizer		
15.15-16.00	Yellow Card Scheme	AAP		Clinical Trial Challenge
16.00-16.45	El Lilly	PRA		
16.45-17.30	Clinical Trial Challenge	COMET (Univ Liv)	TBC	

This Week's Leaders

Conference Leader



Pamela Dicks

Pamela is the manager of the NHS NRS Children's Research Network, formerly the Scottish Children's Research Network, which facilitates and supports a broad portfolio of commercially and public funded clinical trials in paediatrics. The network supports teams of paediatric research nurse in dedicated children's clinical research facilities in NHS Scotland. She also coordinates the network's Young Person's Advisory Group, who are advocates for young people in clinical research. She has been involved with iCAN since the very beginning and is on the Executive Committee. She is a founder of the European Young Persons Advisory Groups Network eYPAGnet and in the Coordinating Group of the European Network of Paediatric Research Networks at the European Medicines Agency (EnprEMA).



Laura McMaster

Laura is a certified clinical research professional (CCRP) and fully licensed marriage and family therapist (LMFT). She has contributed to research and clinical care for children affected by autism, congenital heart defects, and other stressors affecting the whole family system. Laura has studied and worked internationally in the EU. Ms. McMaster draws on her education in Anthropology to find meaningful ways to connect across disciplines and cultures. She is an alum of Emory University, The London School of Economics, and Mercer University. Laura and her husband reside in Atlanta, GA, USA.

Keynote speakers



Steve Cunningham

Steve Cunningham is Professor of Paediatric Respiratory Medicine at the University of Edinburgh, UK. He is Vice Chair of the UK Health Regulatory (MHRA) Paediatric Medicines Expert Advisory Group. Steve is a PI for novel (small molecule) therapies for children with cystic fibrosis. He also researches bronchiolitis. Currently, he is actively involved in developing novel therapeutics and vaccines for the treatment of RSV in young infants.



Elin Haf Davis

Elin Haf Davis has rowed across both the Atlantic and Indian Oceans and then sailed across both the Pacific and the Atlantic. Spending a total of 204 days at sea. Her other passion is to inspire children, especially those with chronic life-long and life-limiting conditions to have the confidence to take charge of their own circumstance. Based on her experience, and the need to improve the drug development pathway Elin co-founded Aparito, a digital health company providing remote patient monitoring in real time.



Paul Dimitri

Professor Paul Dimitri is the NIHR Clinical Research Network National Children's Specialty Lead. He works at Sheffield Children's NHS Foundation Trust. Paul is the Clinical Lead for the TITCH (Technology Innovation Transforming Child Health) Network established to support the development and adoption of technology for children's healthcare. He is also the lead the newly formed NIHR Children & Young People MedTech Cooperative.



Alun Hughes

Dr Alun Hughes is the Director of Teaching for the School of Medicine at the University of St Andrews, where he also teaches physiology and pharmacology on their Medicine programmes. Alun graduated with a BSc (Hons) Pharmacology in 1998 from the University of Aberdeen, before completing his PhD in Cell Biology/Toxicology at the same institute. From his PhD onwards, Alun has been heavily involved in public engagement – from Young Persons' Groups with ScotCRN, to Skeptics in the Pub and the Edinburgh fringe.



Dan Hawcutt

Dr Hawcutt is a senior lecturer in paediatric pharmacology at the University of Liverpool and honorary consultant in paediatrics at Alder Hey Children's Hospital. He is the clinical lead on the NIHR Alder Hey Clinical Research Facility. Dr Hawcutt is also a member of the Medicines and Healthcare Regulatory Agency Pharmacovigilance Expert Advisory Committee. His research interests include pharmacogenomics of adverse drug reactions, early phase clinical trials, and pharmacovigilance.



Bob Phillips

Bob is a Senior Clinical Academic at CRD and an Honorary Consultant in Paediatric / Teenage-Young Adult Oncology at Leeds Children's Hospital. He focuses on the development of individual participant data (IPD) meta-analysis, supportive care management, and developing skills to appraise and translate clinical research in practice. He encourages high-quality health research with youths with life-limiting conditions.



Martina Rodie

Dr Martina Rodie is a Consultant Neonatologist based at The Royal Hospital for Children in Glasgow. She has an interest in differences of sex development (DSD) and rare disease registries. She was involved in the development of the International DSD Registry which was an MRC funded project. She works closely with The Office for Rare Conditions in Glasgow and is currently setting up a working group to evaluate care pathways for children with rare conditions.



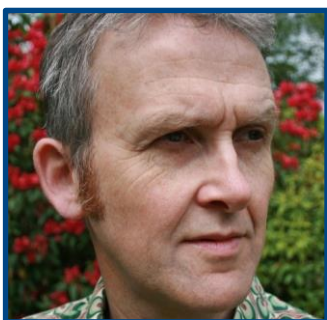
Brian Smith

Brian is visiting lecturer in Music Therapy at Goldsmiths College, Napier University, Trinity College of Music and Strathclyde University. In 2004 Brian became the Music Therapy tutor on the undergraduate programme at Durham University. Brian is managing director of Inscape Therapies, which provides a music therapy service throughout the west and central belt of Scotland. These include the National Autistic Society, Glasgow Education Service, Stirling Education Service, West Dunbarton Social Work Department, East Renfrewshire Education and South Lanarkshire Education.



Vivian Tsang

Vivian is a third year student in the Faculty of Science majoring in population health and therapeutics at the University of British Columbia, Vancouver. She is passionate about young people's engagement in healthcare and is a big advocate for collaboration between paediatric researchers and their target demographic. Currently, she is the Team Leader for KidsCan Vancouver and serves on the iCAN ESC.



Graeme Wilson

Dr Graeme Wilson is a Research Fellow at the Reid School of Music, University of Edinburgh, developing psychological and practice-based research on musical participation and how its application can improve wellbeing. He manages the Scottish Music and Health Network. He has conducted trials and qualitative studies to inform public health interventions, particularly for substance use. Dr. Wilson plays the saxophone and has recorded 25 albums.



Steph Wright

Steph is a Project Development Manager at The Data Lab Innovation Centre and she manages the Cancer Innovation Challenge, a £1M Scottish Funding Council funded project to encourage open innovation in data to improve cancer care in Scotland. She has navigated a career through the arts, then back to the sciences in genomics, then carbon capture, and now data science. Steph specifically has an interest in the use of data science and artificial intelligence in healthcare.

Local Chapters

We are joining together this week to form a united voice heard when all parties learn and work on the future of pediatric research and advocacy. Find your local chapter below!

KIDS (Kids Impacting Disease through Science) chapters are organized across countries, states, cities, and towns. European YPAG's are part of the eYPAGnet, grouped across countries, towns, and cities.

LOCAL PRESENCE	LOCAL LEADER
KIDS Albania	Manika Kreka
KIDS Barcelona	Begonya Escalera
KIDS Bari	Mariangela Lupo
KIDSCan (Canada)	Vivian Tsang
KIDS Central Ohio	Amogha Kirshna
KIDS Connecticut	Sharon Smith
Generation R, England	Jenny Preston
KIDS Florida	Meagan Schnieder
KIDS France	Segolene Gaillard
KIDS Georgia	Stephanie Meisner
KIDS Houston	Carrie Koh
KIDS Illinois	Fred Hebal
KIDS Kansas City	Amanda Woelke
KIDS Michigan	Amy Ohmer
Scot CRN (Scotland)	Pamela Dicks

Want to schedule a meeting, get feedback, or contact a group directly? Speak to a team leader this week!

Felix Junquera-Tejeda Scholarship

Felix was a special and brave person. He was an iCAN teen advisor and former president of KIDS Barcelona. His energy lives on, encouraging his family and friends to be advocates and fighters against rare paediatric cancers.

Young people encourage researchers to improve paediatric medicine, but when youths love science they are the inspiration for other young people to be involved too.

In memory of Felix, ICAN leadership opened a youth scholarship in his name, to be awarded to an essay author.



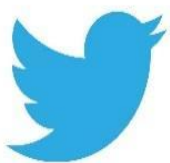
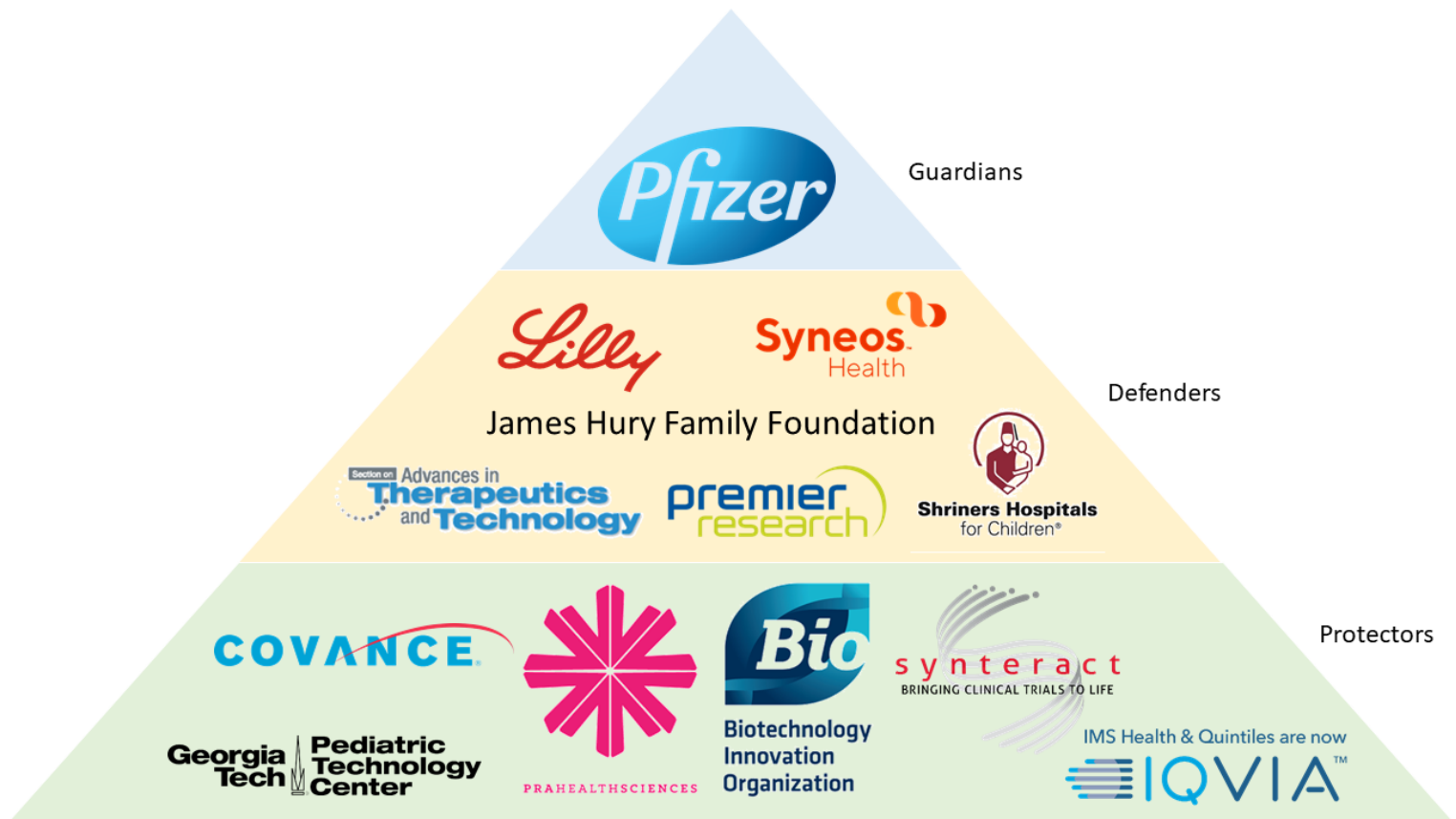
Leadership carefully reviewed each essay and was impressed, as always, with the excellent work of our young authors. KIDS Michigan member Olivia Ohmer was selected as the scholarship recipient for her submission "Why ICAN Is Important to Me." Olivia will receive funding for lodging in Edinburgh during her visit this week! Congratulations to Olivia on her essay in which she shared that any challenges with her health have inspired her to reach out and help others. You may read Olivia's work on our website (www.icanresearch.org).



Use the catering breaks to visit our **Charity Space!**

Sponsorship

We thank the below sponsors for their generous support of the conference!



On Twitter? Follow conversations online with **#iCANsummit18**, and follow us on **@iCANResearch** for updates.

Thank you

We would like to extend a special thanks to all our chairs, speakers, attendants who have contributed to this conference and made this an informative, inspiring and enjoyable week for our delegates and their families.

A special thank you also goes to the Summit Planning Committee, who have been invaluable in creating the programme and keeping everyone engaged.

Pamela Dicks, Manager, Scottish Children's Research Network

Charlie Thompson, Chairman and Founder of iCAN

Leanne West, iCAN President

Christine Woods, iCAN Vice President

Chester Koh, MD, iCAN Secretary

James Hury, iCAN Treasurer

Laura McMaster, iCAN Director

Sharon Smith, MD, KIDS Connecticut President

Chris Logel, iCAN Fundraiser

Jillian Wood, Executive Director of Foundation for Children

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We would also like to thank the venue staff and the **John McIntyre Conference Centre** and **Dynamic Earth** for their support in the planning and delivery of the summit, ScotCRN and NHS Research Scotland staff who have helped with planning and final details, and everyone who volunteered their time and knowledge to make the 2018 event a success.

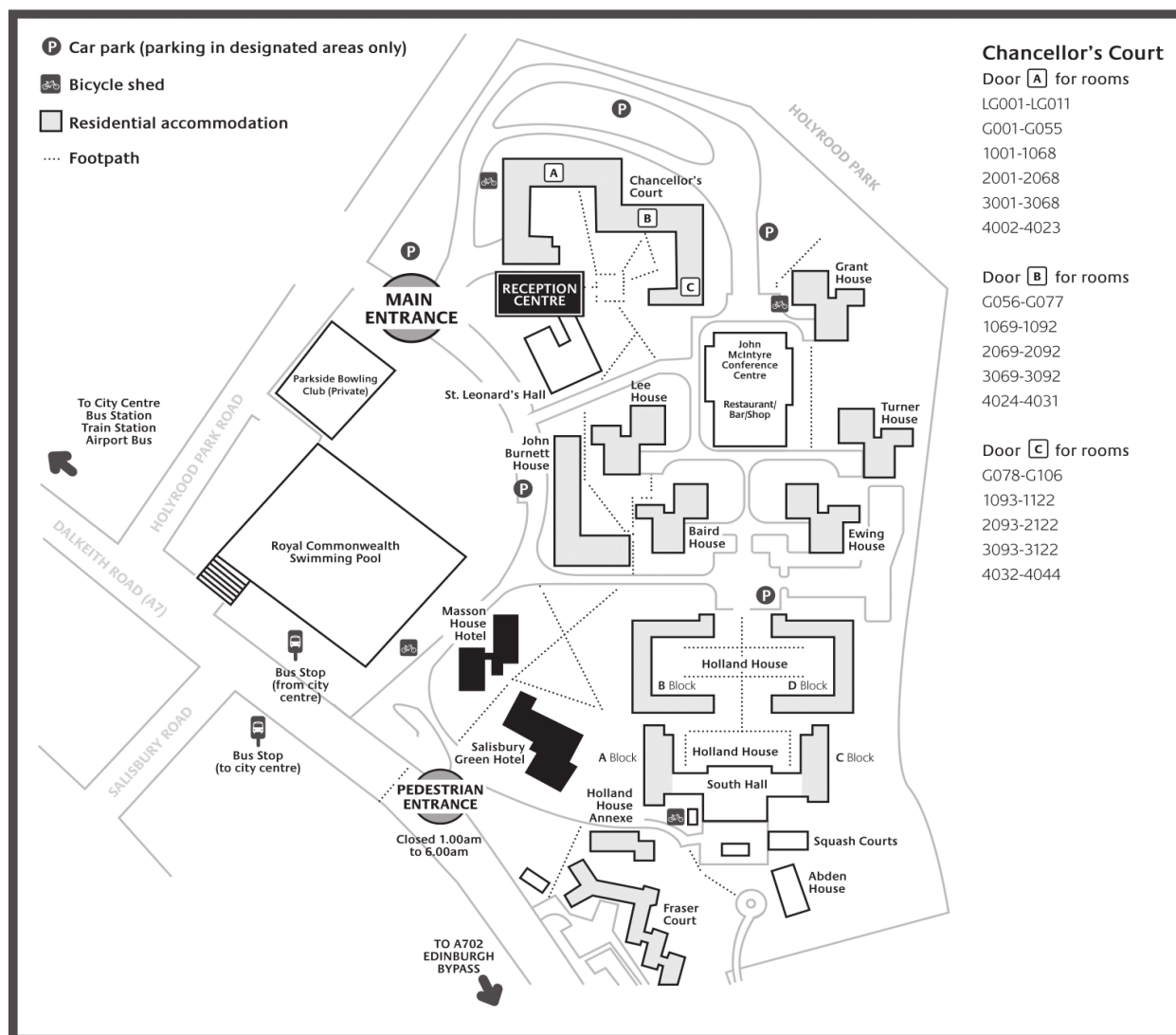
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Pollock Halls



Check out 10.30am on your day of departure

Breakfast is served from 07.30am – 10.00am

Reception may be contacted 24 hours a day, please check your in-room information

Tourist information & tours are available at Reception

Extension of stay please contact Reception the night before your original departure

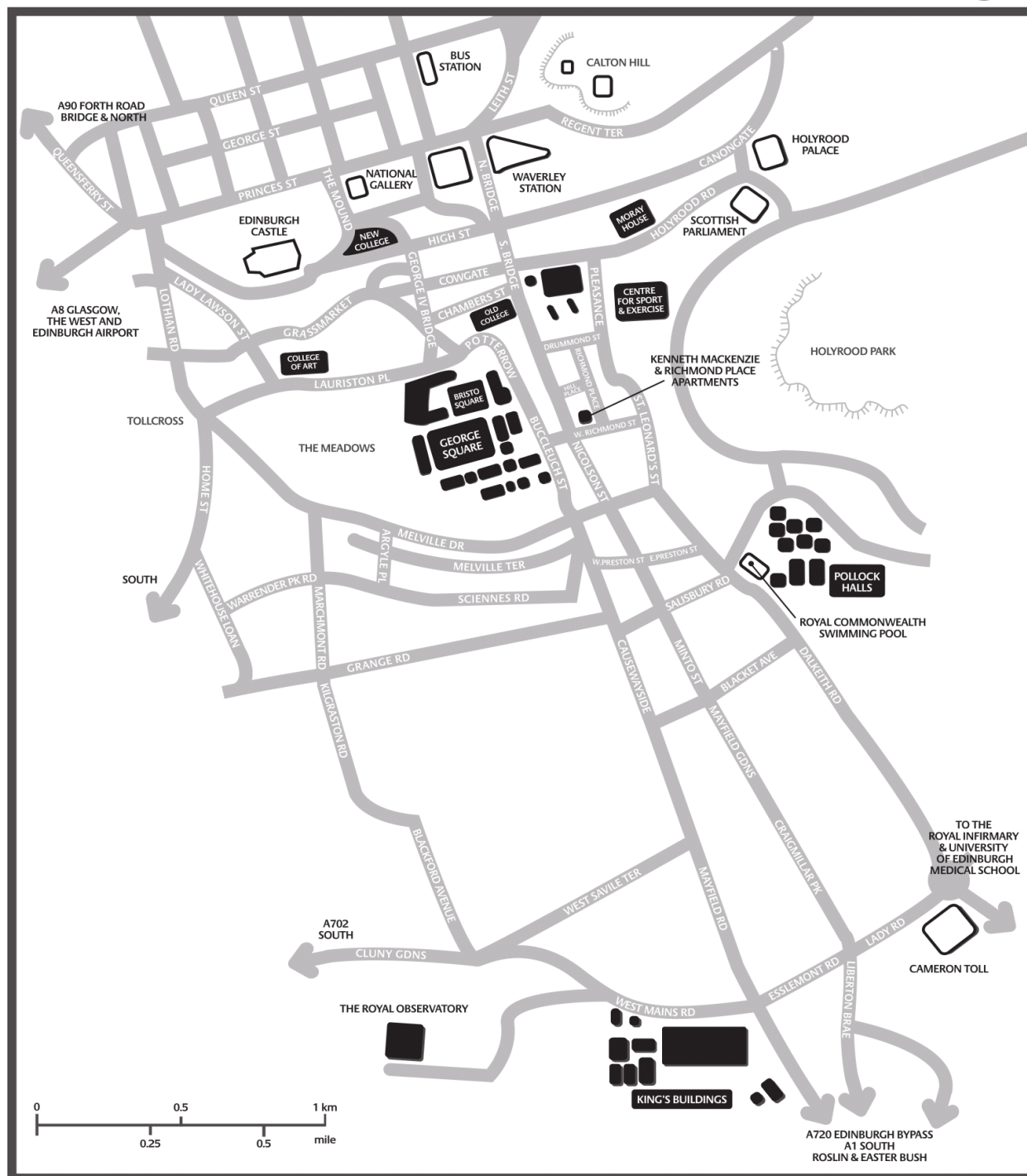
Maps



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Notes

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