



# Portfolio Update

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# Update on Portfolio

- Update on figures
- Where are we now?
- What's holding up study registration?
- Collecting accrual data

## Figures as of 12 June 2008

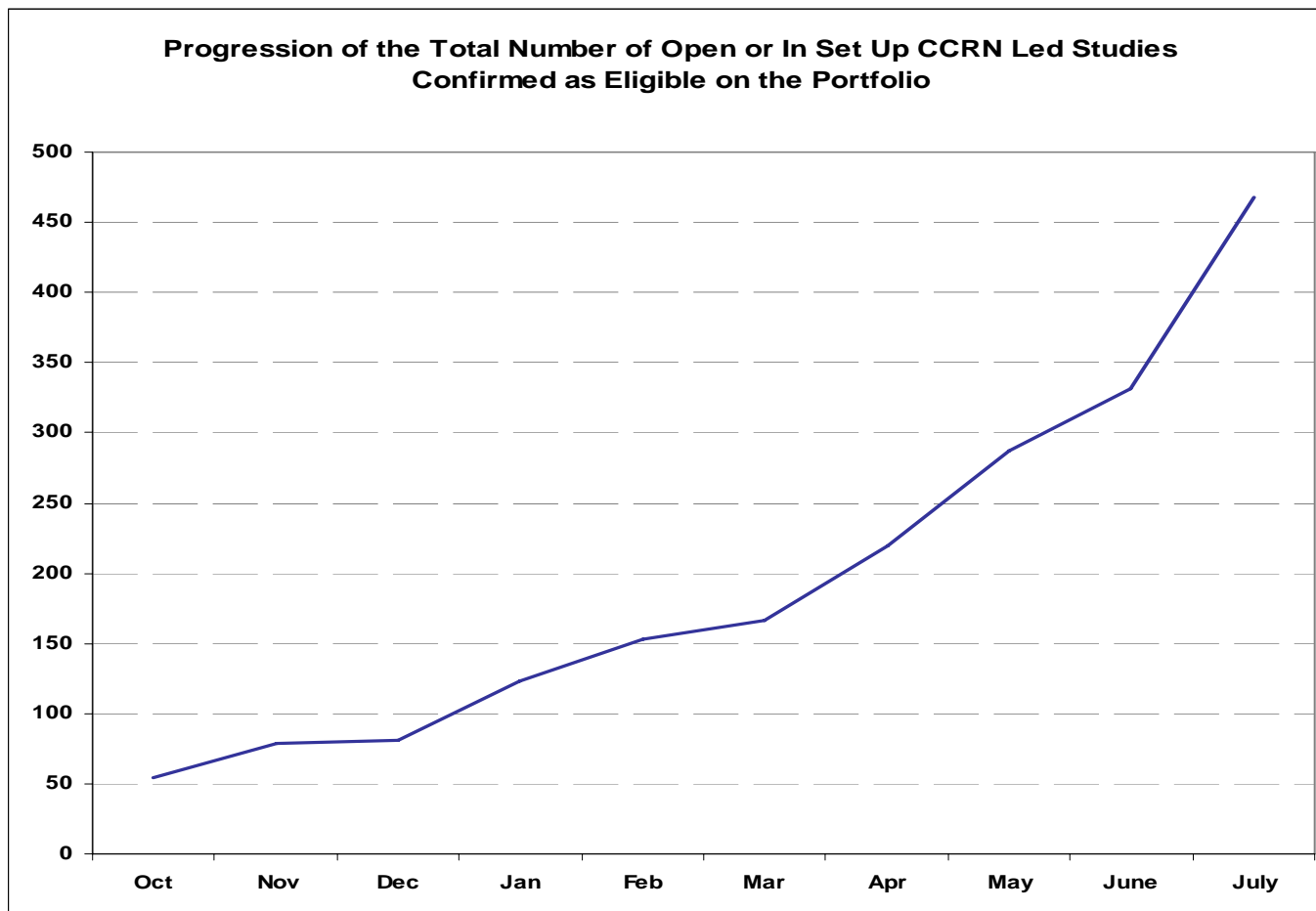
TOPIC	Total Number of Studies Open or In Set Up	Total Number of Studies Reporting Accrual, 2008/09 (April 08 to date)	Total Accrual, 2008/09 (April 08 to date)
Cancer	325	149	1962
Dementias and Neurodegenerative Diseases	53	29	362
Diabetes	86	25	783
Meds for Children	57	20	118
Mental Health	87	8	112
Stroke	44	32	696
PCRN	96	28	3223
CCRN	332	82	3255
<b>TOTAL</b>	<b>1080</b>	<b>373</b>	<b>10511</b>

# Figures as of 7 July 2008

TOPIC	Total Number of Studies Open or In Set Up	Total Number of Studies Reporting Accrual, 2008/09 (April 08 to date)	Total Accrual, 2008/09 (April 08 to date)
Cancer	329	149	2485
Dementias and Neurodegenerative Diseases	62	38	587
Diabetes	96	25	853
Meds for Children	57	22	286
Mental Health	87	10	175
Stroke	48	32	774
PCRN	105	28	3223
CCRN	468 (332)	127 (82)	13944 (3255)
<b>TOTAL</b>	<b>1252</b>	<b>431</b>	<b>22327</b>

Figures as at 7th July 2008

# CCRN studies added to the Portfolio



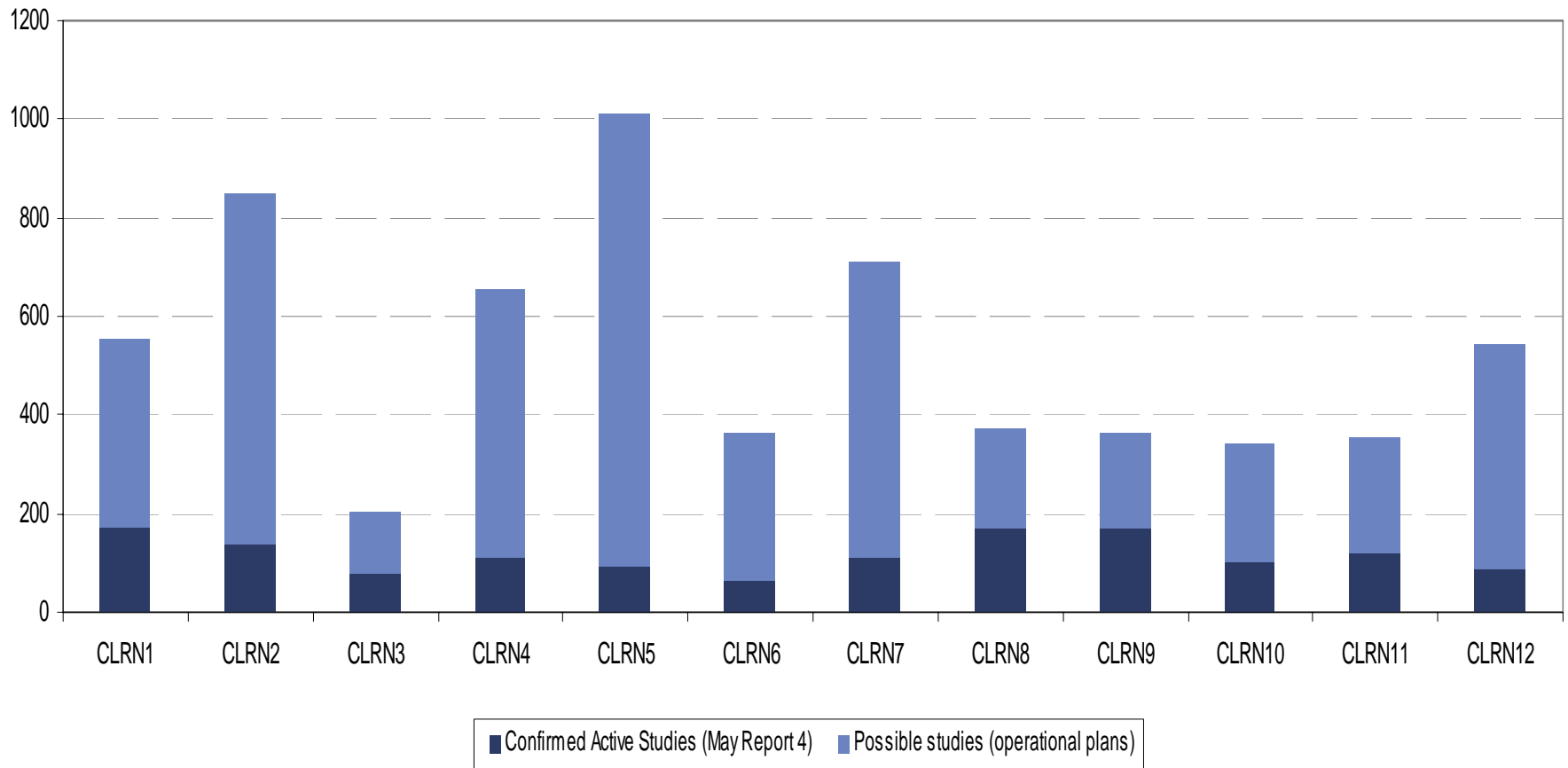
CCRN	Total Number of Studies Open or In Set-Up	Total Accrual, 2008/09 (1 April to date)
Blood	6	5
Cardiovascular	87	273
Congenital Disorders	11	1
Ear	8	10081
Eye	11	0
Generic Health Relevance & Cross Cutting Themes	49	601
Infection	24	13
Inflammatory and Immune	25	42
Injuries and Accidents	6	4
Metabolic and Endocrine	11	8
Musculoskeletal	65	167
Neurological	36	29
Oral and Gastrointestinal	26	57
Renal and Urogenital	11	8
Reproductive Health	37	2578
Respiratory	46	65
Skin	9	12
<b>TOTAL</b>	<b>468</b>	<b>13944</b>

# Where are we now (1)?

- Confirmed around half (?) of all eligible CCRN studies
- Have collected accrual data for about a quarter of these
- = one eighth of the way towards defining CCRN portfolio
- Activity-based funding for 2008-2009 will be based on activity (ALL Networks) from April 2008 to Oct/Nov 2008
- About half way through the reporting period
- Clearly a challenge

# Where are we now (2)?

Confirmed Active Studies from Report 4 (May) vs. the Estimated Total Number of Possible Studies (from Operational Plans)



# What's holding us up with study registration (1)?

- Lack of completed Initial Study Registration Proformas
  - May report listed 795 studies funded by eligible funders but which didn't have completed minimum datasets
  - There are still 685 still outstanding - these are now being removed from the Portfolio DB
- Lack of confirmed NIHR Partner Organisations
  - 46 charities confirmed, 53 written to
  - 265 studies (the majority do not have complete MDSs)
- Process for reviewing non-automatically eligible studies (EU/NIH) and IITs
  - Interim process now running

# What's holding us up with study registration (2)?

- Policy queries
  - Tissue banks, registries, surveillance studies
  - 25 studies
- Experimental Medicine studies
  - Awaiting policy decision from DH on BRCs/CRFs etc.
- Adoption by Topic Specific Networks
  - Consolidating adoption processes and streamlining

# Study Types (1)

- Studies funded by confirmed NIHR Partner Organisations
  - For CCRN, where dataset is COMPLETE, these are confirmed within 5 working days
  - Very few cannot be confirmed as they involve policy queries (eg. registries, tissue banks) which we have referred to the DH
  - Those that fall within the remit of a TCRN/PCRN are referred to the TCRN/PCRN Coordinating Centre – this can cause delays
  - Tidying up database and removing ones which do not have a full MDS
- Studies funded by UK Organisations which are not confirmed as NIHR Partner Organisations
  - Have written to over 50 charities requesting evidence to support NIHR Partner Organisation status – then refer this to the DH for a decision

## Study Types (2)

- Studies funded by non-UK Governments (eg EU/NIH)
  - Have developed an interim adoption process, back-log has now been cleared and regular meetings will turn these around within one month
  - Should now submit these to us (completed)
- Industry-funded, non-industry sponsored (IITs)
  - As above, for those that are recruiting after April 2009 (require further information for some of these)
  - Where recruitment is completed prior to April 2009, not putting these on Portfolio (Transition Funding to be used)
- Industry-funded, industry sponsored
  - Not putting current ones on Portfolio – new ones taken forward by UKCRN Industry team
- Studies funded by non-UK charities
  - Considered to be low priority

# Way of working – study identification

- Will send CLRNs lists of “outstanding studies” so that we all have a joint understanding of the status of individual studies
- Priority should be on studies which are recruiting after April 2008 – automatic, EU/International and IITs
- Happy to register studies which are in follow-up after April 2009 in order to flag resource implications to CLRNs
- Moving towards on-line reporting for “Report 4”
- What else can we do to support you?

# Collection of Accrual Data

- Moved from April 2007 to April 2008
- UKCRN CC taken the lead up until now – to prevent multiple contacts with CIs/accrual contacts
- A huge amount of accrual data is not being collected
- Agree that CLRNs should play a major role in this
- Two parts:
  - getting engagement from CIs to do this
  - Submission of accrual using upload system (technical)
- “accrual” doesn’t make sense for some studies – we are working on this – shouldn’t be a barrier to study registration

# Way of working – accrual data collection

- CLRN identified staff to train in the accrual upload process
- In the middle of training CLRN staff in the accrual process
  - Leeds, London and Birmingham
  - 21 of 25 CLRN taking part in this
- We set up the “data package”
- Technical support from the UKCRN CC (Angela and Vicki)
- Decision for each CLRN to decide whether they want to take full responsibility for chasing up/supporting collection of accrual data
- Responsibility for uploading accrual data rests with the study coordinator
- Some TCRNs are better at chasing accrual data than others – contact TCRN Portfolio Managers about individual studies