

DATA SHARING REPORT

The MRC Policy and Guidance on Sharing of Research Data from Population and Patient Studies requires the production of periodic reports on the nature and scale of data sharing. Table 1 shows a report covering the period April 2014 to March 2019 to provide continuity with in our QQ2015-20 report and the main features are summarised below.

- For each study, the Table shows the total number of data requests made within the audit period and the number that were accepted, both as the total number and a percentage. A total of 495 requests were made. Of these, 484 have been approved and, at the time of writing, 10 were under review pending approval. Only 1 request has been rejected which was an internal request from a member of the Unit; the request related to a proposed GWAS study of educational attainment and was rejected because of insufficient data on educational attainment within the relevant study such that it would not be an effective use of internal resources to undertake the proposed analysis.
- As described in the Unit's Data Management Plan, all external data releases require completion of a data request form and these forms are also now used for internal releases. Table 1 therefore also indicates whether the request was made formally using a data request form (formal releases) or more informally (informal releases). The majority of releases (82%) followed a formal process, with a small proportion of internal releases (16%) following an earlier, informal process. During the initial period of tracking, the formality of the data release request was not always recorded; such requests are shown as 'unknown' in the Table (2%).
- A total of 515 data releases have been made within the audit period. Of these, 390 (76%) were for internal and 125 (24%) were for external use, with 2 external requests were handled through the 'in-reach' approach (section 13.1.4a). Releases to EPIC-Europe are classified as internal since they are within the consortium; releases to ICAD investigators are defined as external.
- Data is made available on a versioned, release by release basis as new participants or data are added to the study. A significant number of data releases (224) have been updated to include new data.
- An indication of the outputs and scientific opportunities arising from the released data is also provided. This uses the number of peer-reviewed papers specifically reporting use of the study data or meta-data that were published during the audit period as a proxy. Publications are sub-divided into those with a Unit first author and those where the first author is external to the Unit in order to provide an indication of internally and externally led research. DOIs are now being used which will enable published outputs to be tracked to individual data releases in future audits.

Table 1: Data release audit covering the period April 2014 to March 2019

	# Master Sets	DATA RELEASES														OUTPUTS			
		Requests made					Process for release request			Releases processed									
		Requested	Accepted	Approval_Pending	%_Accepted	%_Declined	%_Appealed	Formal_Releases	Informal_Releases	Unknown	Total Processed	Requests Processed Internal	Requests Processed External	Request Processed In Reach	Requests Processed Unknown	Release Updates	Total # papers	# papers (unit first author)	# papers (ext. first author)
ACTIVE DATA COLLECTION																			
ADDITION (1)	4	91	91	0	100	0	0	60	61	0	88	60	28	0	0	44	29	19	10
Baby Milk	2	6	6	0	100	0	0	6	0	0	6	2	4	0	0	0	3	3	0
BioBank Validation Study	1	2	2	0	100	0	0	0	0	2	2	0	2	0	0	0	1	1	0
CASE	1	1	1	0	100	0	0	0	1	0	1	1	0	0	0	0	2	2	0
EPIC Norfolk (3)	1	16	14	2	100	0	0	16	0	0	3	2	1	0	0	3	231	44	187
The Fenland Study (2)	9	181	181	0	100	0	0	130	39	12	180	159	21	0	0	74	74	34	40
FRESH	0	4	4	0	100	0	0	4	0	0	4	0	4	0	0	2	1	1	0
GLOW	0	0	0	0	-	-	-	0	0	0	0	0	0	0	0	0	0	0	0
PROPELS	0	3	3	0	100	0	0	2	0	1	3	0	3	0	0	2	3	0	3
Soft Drinks Industry Levy Evaluation	1	1	1	0	100	0	0	1	0	0	1	1	0	0	0	0	0	0	0
The Vitamin D Supplementation Trial	1	2	2	0	100	0	0	2	0	0	2	0	2	0	0	0	2	1	1
WRAP	1	4	4	0	100	0	0	2	2	0	4	3	1	0	0	0	3	2	1
FIELDWORK COMPLETE																			
The M74 Study	1	1	1	0	100	0	0	1	0	0	1	0	1	0	0	0	8	8	0
Diabetes Risk Communication Trial (9)	2	5	5	0	100	0	0	5	0	0	5	3	2	0	0	3	2	1	1
The feedback, Awareness and Behaviour Study (9)	1	5	5	0	100	0	0	5	0	0	5	5	0	0	0	3	0	0	0
Ely	4	10	10	0	100	0	0	10	0	0	10	9	1	0	0	0	17	6	11
Health Impacts of the Cambridgeshire Guided Busway	1	2	2	0	100	0	0	2	0	0	2	2	0	0	0	1	14	14	0
Hertfordshire Birth Cohort Physical Activity Trial	1	0	0	0	-	-	-	0	0	0	0	0	0	0	0	0	1	1	0
InterAct (4)(6)	1	105	96	8	99	1	0	116	11	0	129	112	17	0	0	75	69	35	34
International Childhood Accelerometry Database (7)	3	27	27	0	100	0	0	224	2	0	40	6	32	2	0	12	14	7	7
Norfolk Diabetes Case Control Study	1	1	1	0	100	0	0	0	1	0	1	1	0	0	0	0	1	1	0
Physical Activity Annotation Study	1	0	0	0	-	-	-	0	0	0	0	0	0	0	0	0	0	0	0
iConnect (5)	1	1	1	0	100	0	0	1	0	0	1	0	1	0	0	0	5	5	0
ROOTS	1	1	1	0	100	0	0	1	0	0	1	1	0	0	0	0	6	6	0
Sedentary Time Validation Study	1	1	1	0	100	0	0	0	0	1	1	1	0	0	0	0	-	-	-
Step Test Validation Study	0	0	0	0	-	-	-	0	0	0	0	0	0	0	0	0	0	0	0
SPACE	0	0	0	0	-	-	-	0	0	0	0	0	0	0	0	0	4	4	0
SPEEDY	1	1	1	0	100	0	0	1	0	0	1	0	1	0	0	0	13	11	2
DATA PRESERVATION AND USE																			
Allied Dunbar	1	3	3	0	100	0	0	3	0	0	3	3	0	0	0	0	1	1	0
Cameroon	1	0	0	0	-	-	-	0	0	0	0	0	0	0	0	0	1	1	0
Get Moving	1	1	1	0	100	0	0	1	0	0	1	1	0	0	0	0	1	1	0
GLINT	0	0	0	0	-	-	-	0	0	0	0	0	0	0	0	0	1	1	0
GoActive	2	5	5	0	100	0	0	5	0	0	5	5	0	0	0	0	1	1	0
INFORM	1	7	7	0	100	0	0	6	1	0	7	5	2	0	0	1	8	6	2
LLHW	0	1	1	0	100	0	0	0	1	0	1	1	0	0	0	0	-	-	-
ProActive	1	7	7	0	100	0	0	6	1	0	7	7	0	0	0	4	2	1	1
TOTAL	48	495	484	10	1	0	610	120	16	515	390	123	2	0	224	518	218	300	

Notes:

- (1) Includes ADDITION - Cambridge, ADDITION-Plus, ADDITION - Europe, ADDITION TCI and ADDITION 10%
- (2) Includes the Fenland Measurement Reactivity dataset
- (3) EPIC Norfolk releases were the responsibility of a different Department until March 2019 and were not tracked. Study is now transferred to the Unit, with tracking of releases
- (4) Includes InterAct Physical Activity Assessment Validation Study
- (5) Includes iConnect Cheshunt
- (6) Internal means internal to EPIC Europe.
- (7) ICAD: Previous audits have defined Internal as internal to ICAD project group. Now defined as internal to Unit.
- (8) This was a feasibility study, no data releases done

