



Imperial College London Diabetes Centre Repository





Objective

To set up a highly regulated and secure resource that can support a diverse range of research intended to improve the prevention, diagnosis and treatment of illness.



Planning

- ICLDC REC approval has been obtained for this project.
- Research Tissue Bank authorisation has been obtained from Health Authority Abu Dhabi.
- Necessary equipment and space for sample storage have been secured.
- ICLDC staff training on participant recruitment and data management completed.



ICLDC Repository Documentation

- Informed consent form (Adult and Parent/Guardian)
- Information leaflet
- Withdrawal form
- Questionnaire

ICLDC Repository Questionnaire

ICLDC No. _____
Date _____

ICLDC Repository Questionnaire

The following questionnaire will take about 10 minutes to complete. If you need any assistance, ICLDC Repository dedicated staff will be available to answer any of your queries or to help you fill in the questionnaire. Please answer only the relevant questions (the 'male only' or the 'female only' sections) and if there are any questions you do not wish to answer, please skip the question and go onto the next one. Please be reassured that all of your answers will be treated with absolute confidentiality. The information you give us will have your name and address removed, so that no individual could ever be identified by researchers using the data.

Please indicate your choice by shading the number in-between the brackets
For example, to indicate your answer as number four, shade over the [04] to appear like this: [04]

Questions About Your General Health

1. In general how would you rate your overall health?

[01] Excellent [02] Good [03] Fair
[04] Poor [05] Do not know

2. Do you have any long-standing illness, disability or infirmity?

[01] Yes [02] No [03] Do not know

3. In the last year have you had any falls?

[01] No falls [02] Only one fall [03] More than one fall

4. Compared with one year ago, has your weight changed?

[01] No - weigh about the same [02] Yes - gained weight [03] Yes - lost weight

5. Have you had any major operations? (for example, operations that required an overnight stay in hospital).

[01] Yes [02] No [03] Do not know

6. Have you ever had surgery on the arteries of your legs (other than for varicose veins)?

[01] Yes [02] No [03] Do not know

7. Have you ever had surgery to remove any of the following?

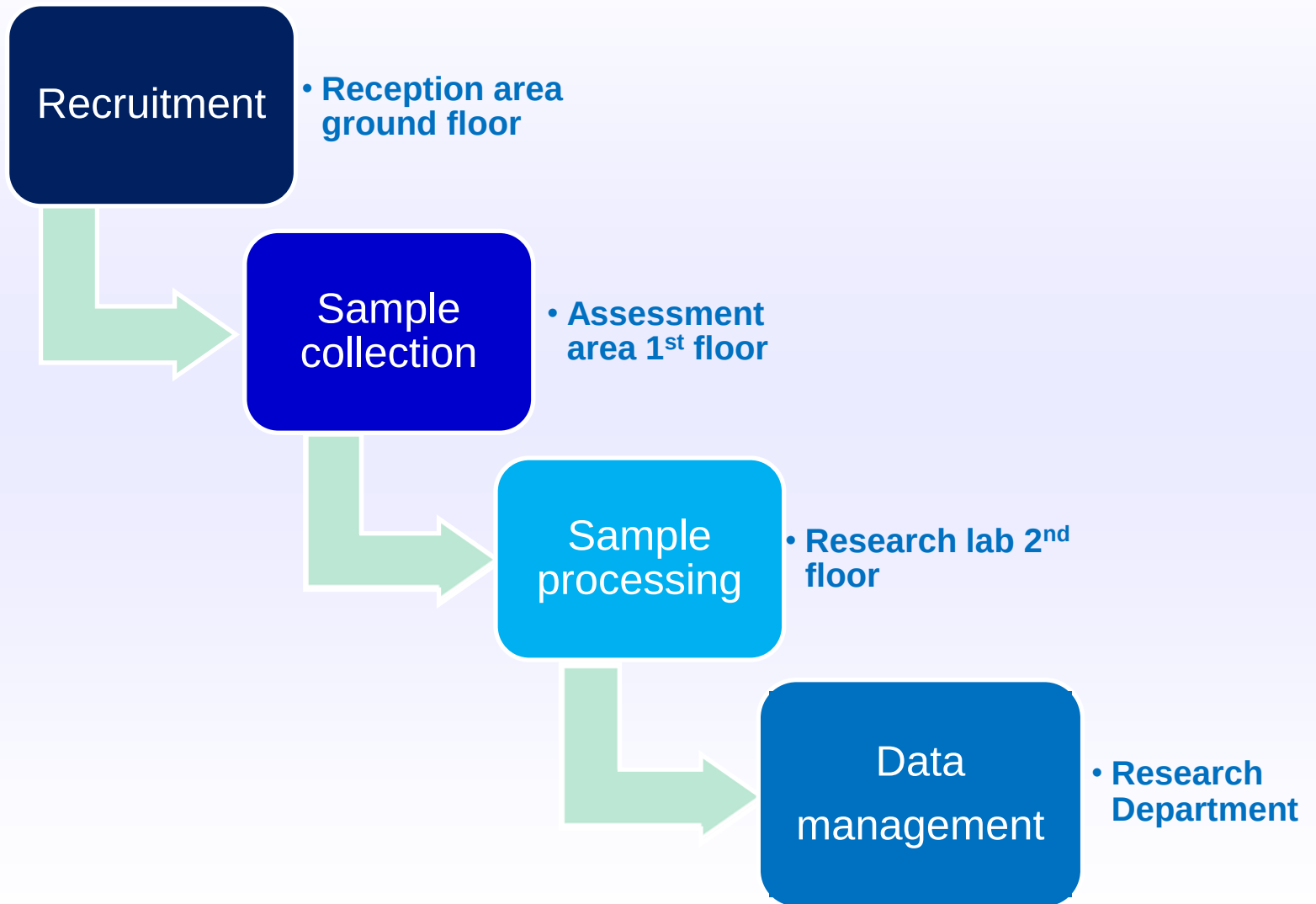
[01] Toes [02] Leg below the knee [03] Leg above the knee
[04] No [05] Do not know

If you decide to allow your data to be used in research, you will be asked to confirm your choice by giving your signed consent, by ticking one or the other. You will be asked to confirm your choice of withdrawal with a signature on a separate consent withdrawal form.

ICLDC Repository
Phone: 02-4040800



Workflow





ICLDC Repository Pilot Run

- First sample collection September 2013
- Pilot run for 3 days to assess the workflow
- 90 patients recruited with ~5% refusal





Keeping Records

- All data is maintained in DIAMOND, the patient management system at ICLDC. This includes:
 - Participation Consent
 - Types of samples collected
 - Number of aliquots processed
 - Location of the aliquots
 - Questionnaire returned

- A manual database is also maintained by the laboratory and is used to check the data in the system



Participation Consent

- Participation Consent is captured in 2 ways:
 1. A box is ticked in the patient record at consent
 2. Signed consent form is scanned and uploaded into the patient record

- If a person refuses to participate or withdraws then tick boxes in the patient record can be used accordingly



Types of samples collected

When a patient is consented the list of samples to be collected is added to the patient record depending on their profile:

Adult patient	Pediatric patient
Blood – purple tube	Saliva
Blood – green tube	
Blood – yellow tube	
Urine	

To record if a sample is

- collected it is marked “Complete”
- not collected it is marked “Cancelled”



Number of aliquots processed

- The laboratory technicians process the samples accordingly and add the number of aliquots of each type in the patient record

– Plasma	Purple tube
– Buffy Coat	
– Red Blood Cells	
– Whole Blood	
– Plasma	Green tube
– Serum	Yellow tube
– Urine	
– Saliva	



Other information in DIAMOND

- Other data is captured in the Notes section of the day's visit in a manner that allows it to be audited. This includes:
 - The location of the aliquots stored (e.g. Box 123)
 - If the patient returned the questionnaire (Questionnaire)



Reporting

- On a daily basis, a report is run and the data is compared with that available in the manual database.
- Any discrepancies are verified against the physical samples available in storage.
- Participant responses to the questionnaires are captured manually in a separate database linked by the patient ID.
- Any clinical data required about the patient can be readily extracted from DIAMOND.



Example of the participant database

ICLDC No.	Consent Date	Added by	Package	LOCATION	CONSENT	REFUSED	WITHDRAW	NOTE ON CONSENT
A029650	14/12/2014	Samia Jibar	Z Research Repository	Abu Dhabi	Yes	No		
A035169	14/12/2014	Samia Jibar	Z Research Repository	Abu Dhabi	Yes	No		
A082255	14/12/2014	Samia Jibar	Z Research Repository	Abu Dhabi	Yes	No		
A091781	14/12/2014	Samia Jibar	Z Research Repository	Abu Dhabi	Yes	No		
A130647	14/12/2014	Samia Jibar	Z Research Repository	Abu Dhabi	Yes	No		
A134925	14/12/2014	Samia Jibar	Z Research Repository	Abu Dhabi	Yes	No		
A139449	14/12/2014	Samia Jibar	Z Research Repository	Abu Dhabi	Yes	No		Nurse unable to collect samples
A146252	14/12/2014	Samia Jibar	Z Research Repository	Abu Dhabi	Yes	No		
A146296	14/12/2014	Samia Jibar	Z Research Repository (Paediatric)	Abu Dhabi	Yes	No		
A146314	14/12/2014	Samia Jibar	Z Research Repository	Abu Dhabi	Yes	No		

ICLDC No.	Consent Date	QUESTIONNAIRE	PLASMA (PURPLE)	BUFFY COAT (PURPLE)	RBC (PURPLE)	WHOLE BLOOD (PURPLE)	PLASMA (GREEN)	SERUM (YELLOW)	URINE	SALIVA	BOX NUMBER
A029650	14/12/2014		3	1	2	4	2	2	4		425
A035169	14/12/2014	Yes	3	1	2	4	2	2	4		425
A082255	14/12/2014		3	1	2	4	1	2	4		424
A091781	14/12/2014		3	1	2	4	2	2	4		425
A130647	14/12/2014		3	1	2	4	2	2	4		424
A134925	14/12/2014		3	1	2	4	1	2	4		425
A139449	14/12/2014		No samples	No samples	No samples	No samples	No samples	No samples	No samples	No samples	
A146252	14/12/2014		3	1	2	4	2	2	4		426
A146296	14/12/2014									2	306
A146314	14/12/2014		3	1	2	4	2	2	4		424



Where Are We Now?

- ICLDC Repository officially started November 2013
- Up to date 2,484 patients have been recruited for ICLDC Repository.
- 7% refusal after consent
- There are currently 30,915 aliquots of various blood fractions (including, EDTA whole blood, EDTA plasma, red blood cells, EDTA buffy coat, heparin plasma, SST II serum, urine).
- 33% patients recruited completed questionnaire
- There are also 762 saliva aliquot samples collected from paediatric cases, to be used for genetic analyses.



Challenges

- Local population attitude towards research
- Integration of ICLDC Repository into everyday centre practice
- Questionnaire data handling
- Sample quality control check
- Keeping records



THANK YOU

