

APPENDIX: ANONYMISED LIST OF INTERVIEWEES AND BACKGROUND DETAILS

<i>Name</i>	<i>Principal health issue(s) discussed</i>	<i>Background (gender, age, equality group, social education or status)</i>	<i>Interview with (and date)</i>	<i>Key issues</i>
<i>Chapter 2: Pregnancy and childbirth</i>				
Cathy	Recently gave birth	Female, 30s White English Healthcare professional	Jeremy February 2020	Very difficult birth, mostly well handled, with a few lapses in care; some reflections on what constitutes good maternity care; implications for professional practice.
James	Carer for mum with dementia and now new dad	Male, 50s White English Secondary education, professional	Naomi February 2020	As new dad, positive experiences of being included by maternity staff. Trauma of birth for his partner not well handled by NHS.
<i>Chapter 3: Children and young people</i>				
Dan	Teenage boy. Story told by dad, Jonathan	Male, 16 White British Middle-class professional background	Naomi June 2020	Experience of hospitalisation for acute illness during the COVID-19 pandemic.

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Jim	Young man living with severe disabilities who died aged 36. Story told by parents Justin and Lucinda	Male, from birth to 36 White English Middle-class professional background	Naomi June 2020	Difficulties of caring for a young man with serious disabilities.
Eve	Remembering a childhood diagnosis of type 1 diabetes	Female	Naomi January 2018	
Finbar	Scoliosis. Story told by parent Eileen	Male, teenager Middle-class background	Naomi December 2019	Length of time to get to see specialist consultant in tertiary facility. GP (and mum) knew diagnosis but they still had to go through hospital consultant for onward referral. Mum tracked and chivvied tertiary unit for appointments and to make sure operation was scheduled. Experience of support group very helpful.

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<i>Chapter 4: Managing a long-term health condition as an adult</i>				
Katie	Diabetes, other conditions	Female, 50s White English Secondary education. Not able to work	Naomi April 2018	Ups and downs of getting good care for type 1 diabetes and complications. Postcode lottery battle to get continuous testing device on the NHS. Kindness of some of the GPs at the practice – also not having to repeat oneself. Very difficult to access mental health support to tackle the psychological impact of this long-term condition; husband has never been offered support as a carer.
Tim	Epilepsy	Male, 30s White English Middle-class background	Jeremy January 2020	Difficulty of living with epilepsy; stigma; drugs balancing act; importance of family and friends; great nurses and paramedics; good and bad doctor experiences; difficulty of finding a good specialist; pros and cons of support groups: “I am more than epilepsy”.

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Joanna	Various long-term conditions, including rare condition. Also parent carer of child with long-term conditions	Female, adult White English Professional	Jeremy January 2020	High-handed doctors; difficulty of getting diagnosis; fragmentation of care; poor basic administration; difficulty of getting improvements without formal complaints.
Jasmin	Lupus	Female, 30s BAME Middle-class	Jeremy February 2020	Four years to get a diagnosis of lupus; “I knew something was wrong. I wasn’t listened to”; private doctors got to the bottom of the problem; “my whole body was shutting down”; pros and cons of belonging to a support group; poor experience of NHS physiotherapy; generally having to battle.
Venetia	Chronic fatigue syndrome	Female, late 20s White English University degree. Works in admin	Naomi June 2017	Lack of support for the condition, particularly from GP; pros and cons of support group; having to search oneself to understand the condition; lack of local clinical service.

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<i>Chapter 5: Adult acute care and cancer</i>				
Jill	Accident – dislocated knee	Female, 50s White English Professional, former teacher	Jeremy January 2020	Waiting for an ambulance; pain; great nurses; brusque doctors; successful rehab but had to fight for it; poor organisation of wound care.
Andrea	Surgery – gallbladder operation	Female, older White English Left school at 16. Manual work in hotel industry	Naomi December 2019	Successful outcome; pleased with lack of waiting; care seemed to be well coordinated; surprised to be treated in a private hospital as an NHS patient.
Lucy	Sepsis	Female, older White English Retired healthcare professional	Naomi April 2018	Hospitalised with sepsis; experience of different quality of care and treatment on different wards; problem with accessing medical records between hospitals; patient lives with severe and enduring mental illness.
Shona	Breast cancer	Female, 40s BAME	Jeremy June 2020	Experiences of being diagnosed with breast cancer; treatment and of living as a cancer survivor.

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<i>Chapter 6: Mental health and mental illness</i>				
Audrey	Family member of mental health service user	Female, 30s White English Healthcare professional	Naomi December 2016	Length of time to get diagnosis of severe mental health problem for family member.
Stanley	Mental health – bipolar disorder	Male, 40s Black African	Jeremy December 2019	The importance of seeing the person; the importance of work to mental health; stigma.
Alan	Mental health – bipolar disorder	Male, 40s White English University degree	Jeremy December 2019	Continuity of care; therapeutic relationship; poorly designed services; patient participation as a route to personal development.
Nathan	Mental health	Male, teenager White, English, gay	Jeremy January 2020	Human qualities of the therapist; continuity of care; being believed; impact of diagnosis/misdiagnosis; labelling; importance of NHS/school liaison; importance of good receptionists.
Lucy	Lifelong severe and enduring mental illness	Female, older White English Retired healthcare professional	Naomi April 2018	Lack of communication between hospital and primary care for mental health problems.

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<i>Chapter 7: Older age and end of life</i>				
Robert	Bowel and heart problems	Male, 80s White English University degree, retired manager	Naomi January 2020	Involved in patient participation after retirement; various illnesses, including stomach problem, heart attack and joint problems; fragmentation in the NHS; lack of clarity on role of district/community nurse.
Rabiya	Carer of mum with dementia	Female, 30s Muslim Asian University degree, professional	Naomi February 2020	Struggles with getting diagnosis for mum; experiences of discrimination; poor support from general practice and other parts of NHS and social care; one episode of real kindness from a physio.
James	Carer for mum with dementia and now new dad	Male, 50s White English Secondary education, professional	Naomi February 2020	Looked after mum for many years, put life on hold to do this; issues and good and bad stories; patient participation, particularly around needs of carers.

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Sheila	Wife of man with a diagnosis of dementia	Female, 60s White English University degree, retired professional	Naomi December 2017	Difficulty in getting diagnosis; battle to get care in place; poor experiences of GP practice.
Kauri	Carer of dad who had pancreatic cancer	Female, 40s Sikh Asian University degree, professional	Naomi February 2020	Many episodes of excellent care and support from hospital and GP; delay in diagnosis; three-month hospital stay; end-of-life care supported by district nurses, visiting hospice staff and GP; challenge from managing the wider family.