Interview Schedule EXTRA – DRAFT 1.0

1. **Structural, spatial, and systemic disadvantages are important factors that inhibit active engagement with formal healthcare and self-management.** 
   1. **Socio-economic status**

*Main question: How do you think your age/gender/income affects your health (physical; mental) and your experience of health care?*

Prompts for patients:

* What are the costs associated with caring for your health?
* Are there things that you need to take care of your health that you cannot afford (medicines or remedies other than from the clinic; food; aids; services)?
* How does your age affect your access to health services, or the way HCPs treat you or talk to you?
* Is there anything that you do to try and overcome such difficulties?

Prompts for carers:

* What are your thought about these issues?
* Is there anything you would like to add which have not been addressed?
  1. **Spatial location**

*Main question: What are some of the difficulties you experience in getting to health services (clinic; hospital)?*

Prompts for patients:

* How do you think time, work and family commitments and transport impacts your ability to get care (go to the clinic, get medication, etc)?
* How do you think the area in which you live affects your ability to manage your health well (crime; diet; physical activity; availability of community resources)?
* Are you able to afford the medication, aids, and services you need? (if yes …)
* What do you need to do to overcome the challenges you experience?
* How does your age affect your access to health services, or the way HCPs treat you or talk to you?

Prompts for the carer:

* What are the difficulties you, as the carer, experience in helping the patient access services?
* What are your thoughts/feelings about these issues?

1. **System quality**

*Main question: What is your experience of the health services you use? What is good/not so good? What would you like to see improved/changed?*

Prompts for patients

* How would you describe your interactions with healthcare services and healthcare providers?
* What work would you say requires you to engage with health services and healthcare providers?
* Are there specific system or professional problems that you need to overcome? What do these look like?
* How easy is it once you are there, to know what you need to do, where to go to get the assistance you need from clinic staff?

*HC environment*

* Can you tell me more about the quality of the facilities (cleanliness; security; comfort; toilets)?

*Organisational*

* What do you think of the way the health services are organized (opening and closing times; waiting times; queue management; co-ordination and continuity of care; role of different *HCPs;* location of pharmacy; referral; pt records)?

*Clinical staff*

* What is your experience of the drs and nurses (perceived expertise/clinical skills; professionalism; attitude to pts - way they treat and talk to pts)?

*Other staff* (security; admin)

* How professional and efficient are other staff at the clinic? How would you describe the way staff engage with the services and patients?

1. **Patients and caregivers experience multiple affective, cognitive, and interactional disadvantages as they seek to participate in encounters with clinicians, decisions about their formal healthcare and self-management processes. Cognitive advantage**

Prompts for patients

* Can you tell me what information you want to find out about your health problems?
* Who do you need to engage with to do this? What work does require you to do?
* When you receive the information, how do you relate it to your circumstance?
* What do participants do to understand and prepare for symptoms and their exacerbation, what work is involved in this, what support is available?
* What do you understand about your conditions?
* How have you gained info/knowledge about your different conditions and how to take care of your health?
* What would you say are your best sources of information?
* Do you trust this information?
* Do you get different information from different sources that you find confusing?
* How do you make this information relevance to your personal circumstances?
* What do you think you know enough about? And what would you like to know more about?
* When you experience symptoms that concern you and you need to understand more about them, where do you go to get information and support?

Prompts for the carer:

* How have you learnt about these conditions of the patient? How do help the patient manage the condition?
* How well informed do you think you are about the condition?
* Have you had access to any resources which specifically address your needs as a carer? If so, please describe. [what are the needs of the patient you care for?]

1. **Affective state**

*Main question: How has having more than one health condition or illness affected you emotionally?*

Prompts for patients

* How do you experience and manage issues connected with stigma, self-esteem, and social functioning?
* What problems would you say you face?
* What do you need to do to achieve this? (to address the problems)
* How did getting a diagnosis of another chronic or long-term condition/s affect you emotionally?
* Which one would you say has had the greatest impact on you?
* Who can you depend on for emotional support?
* H
* as having more than one chronic condition affected your personal relationships in any way?
* Has it affected the way you see yourself or think about yourself?

Prompts for the carer:

* Do you have anything you would like to add from your perspective?
* How have you coped emotionally as the patients main carer?

1. **Interaction quality**

*Main question: Patients and caregivers value resilience, functional performance and social support that make a practical contribution to formal healthcare and self-management.*

Prompts for the patient:

* How would you describe your relationship with HCPs (drs and nurses)?
* How would you say they help you?
* How do you feel when interacting with them?
* How are you in the interaction with them?
* How do you feel about decision making in relation to how to manage your health?
* What do you think would improve the quality of your interaction with your HCPs?
* Does having more than one chronic condition change anything in your relationship with HCPs?

For the carer:

* What is your experience of interacting with the HCP when you accompany the patient?

1. **Adaptation to disruption**

*Main question: What do participants do to adapt to their health and healthcare problems?*

Prompts for the patient:

* How do you experience physiological and psychological effects and limitations?
* What self-management strategies do you use (if any)?
* How do you ‘smooth out’ the disruptive effects of health and healthcare problems?
* How has having more than one chronic condition changed your life (physical & psychological effects; limitations on way of life, work, and routines)
* How has it impacted your relationships, family life?
* How was it to have a second or third or more chronic conditions to cope with?
* How have you coped with these changes?
* What has helped you adapt to living with two or more chronic conditions?
* How easy or difficult has it been to accept our situation?
* How have you overcome some of the difficulties you have faced?
* How do you manage work in your situation (time off for appointments and illness; attitude of co-workers and boss; limitations on ambitions?)

For the carer:

* How has your caring role affected or changed your life (eg: limited your activities; changed your routine and relationships)?
* How have you adapted to these changes?

1. **Caregiver support**

*Main question: Who is helping/supporting patients manage their healthcare? Understanding the caregivers*

Prompts for the patient:

* How do you enroll/get others into helping and supporting you?
* What do you need to do to reciprocate?
* How do caregivers integrate supportive work into their daily lives (do they ration care, time, emotional support etc)?
* Who are the people who help you most in managing your health?
* In what ways do they help you?
* How do you get the support you need from them?
* What do you need to do to reciprocate?

For the carer:

* How do you cope with your care-giving role? How do you feel about it?

1. **Competence**

*Main question: What do participants need to do to demonstrate that they are competent and compliant users of health and healthcare services? What are the tasks that come from participating in healthcare?*

Prompts for patients:

* What tasks do you need to do to manage/control your different health conditions (at home/work, re health services)?
* How did having a diagnosis of a further condition/s add to your tasks?
* What tasks are you managing well/not so well, and why? What could help you manage certain tasks better?
* What makes it hard to manage all these tasks for you?

For the carer:

* What are your tasks as the main carer?
* What makes it hard to manage all these tasks?
* What could help you in your role?

1. **Help seeking**

*Main question: What help-seeking activities are routinely experienced by participants?*

Prompts for the patient:

* What help-seeking activities are experienced by participants in emergencies?
* How (and by who) is an emergency defined?
* What processes lead to in-patient care as a solution to emergencies, and who interacts with healthcare providers to organize and manage these processes?
* Do you feel able to ask for help and get everything you need? Do you know where to get help from?
* What do you do when you need urgent help with your condition? Who helps you make decisions in a health crisis?
* Have you ever experienced a health emergency? If so, can you tell me how you went about getting help and making decisions about what do to?
* Has having multiple chronic conditions made it easier or more difficult in getting the healthcare you need?

*For the carer:*

* Have you ever had to help the patient get help in a health crisis? If yes, what did you do?

1. **Technological support**

*Main question: What kinds of hardware are available to participants? How to they use these to manage their health and healthcare problems?*

Prompts for patients:

* What do you know about any technologies, (eg something on your cell phone that measures exercise or reminds you to take medication; or a glucose meter or blood pressure machine) that can help you manage your condition?
* Do you use any? If so, how do they help? If not, why not?
* What aids would you like to have to help you?

For the carer:

* Do you know of any technologies that could help you with your caring tasks? If yes, please describe.
* If not, would these look for you?

1. **Situated decision-making**

Main question:

Prompts for the patient

* How have you experienced pathophysiological deterioration?
* How do you (and potentially other carers) manage uncertainty over treatment regimens/routines?
* What have been the outcomes of treatment and care processes, and negotiations about access to care?
* What techniques do you use to control their experiences of health and healthcare?
* How confident are you about managing all the tasks and decisions involved in managing your health condition and getting the care you need?
* How much control do you feel you have over how to manage your condition?

Prompts for patients:

* How easy or difficult do you find all these activities?
* How do you feel when things feel out of control (eg. When you have symptoms and do not feel well)?
* And what helps make you feel more in control again?
* What are your expectations of your health in the future?
* What do you expect from the health services in the future?
* How confident do you feel about the quality of the healthcare you will receive in the future?

For the carer:

* How do you see your role in the future? What are your expectations for how things are going to be going forward?