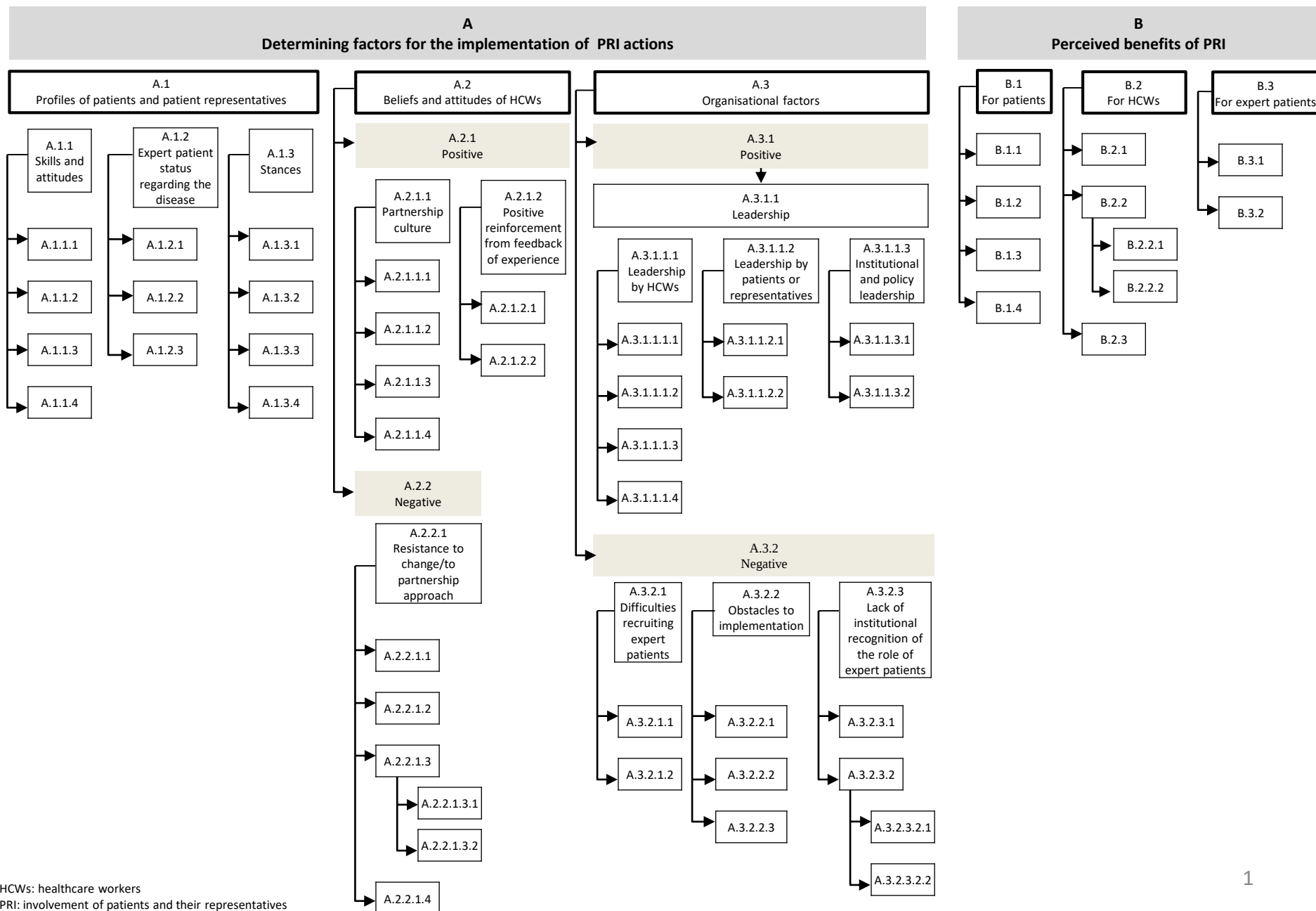


Additional file 3: Coding tree

CONDITIONS AND CHALLENGES FOR INVOLVEMENT OF PATIENTS AND THEIR REPRESENTATIVES IN HEALTHCARE



Coding (themes and sub-themes):

A-Determining factors for the implementation of PRI actions

A.1

A.1.1

A.1.1.1-motivation to collaborate

A.1.1.2-positive and dynamic attitude

A.1.1.3-abilities for oral communication and exchange

A.1.1.4-ability to integrate into a team

A.1.2

A.1.2.1-being concerned by the pathology

A.1.2.2-long-term experience of the care trajectory reflecting knowledge derived from experience

A.1.2.3-balanced attitude towards the care trajectory with the disease (physical and mental dimensions)

A.1.3

A.1.3.1-distancing of personal experience to reach more universal experience (expert patients)

A.1.3.2-distancing of personal experience so as to avoid excessive vulnerability (expert patients)

A.1.3.3-knowing one's role as a partner, its place and its limits

A.1.3.4-training to adopt the right attitudes

A.2

A.2.1

A.2.1.1

A.2.1.1.1-strong adherence to partnership approach

A.2.1.1.2-values shared with colleagues

A.2.1.1.3-teamwork

A.2.1.1.4-networking

A.2.1.2

A.2.1.2.1-positive experiences of patient involvement

A.2.1.2.2-positive feedback from patients

A.2.2

A.2.2.1

A.2.2.1.1-little awareness of the partnership culture

A.2.2.1.2-undermining of professional practices

A.2.2.1.3-fears linked to the professionalisation of expert patients

A.2.2.1.3.1-appearance of competition between expert patients and HCWs

A.2.2.1.3.2-loss of authenticity of patient discourse

A.2.2.1.4-reluctance towards integrating the associative sector into hospitals

A.3

A.3.1

A.3.1.1

A.3.1.1.1

A.3.1.1.1.1-motivation of the HCWs

A.3.1.1.1.2-dissemination of practices via networks

A.3.1.1.1.3-support by experienced HCWs for their colleagues

A.3.1.1.1.4-methodological back-up by qualified team within the facility

A.3.1.1.2

A.3.1.1.2.1-motivation of the patients and their representatives

A.3.1.1.2.2-partnership with associations: impetus and support from patient associations

A.3.1.1.3

A.3.1.1.3.1-institutional formalisation of the participative approach on national or regional level

A.3.1.1.3.2-strategic support from facility management and the hierarchy

A.3.2

A.3.2.1

A.3.2.1.1-restricted availability

A.3.2.1.2-certain volunteering expert patient profiles are unsuitable

A.3.2.2

A.3.2.2.1-funding absent or short-lived

A.3.2.2.2-lack of methodological support

A.3.2.2.3-professionals lack time

A.3.2.3

A.3.2.3.1-volunteer status restricts participation

A.3.2.3.2-difficulty in accessing training

A.3.2.3.2.1-lack of financial support

A.3.2.3.2.2-inadequate training programs

B-Perceived benefits of PRI

B.1

B.1.1-the expert patient personifies hope by embodying a recovery model

B.1.2-complementary knowledge: contribution of knowledge and tools to complement the medical care approach

B.1.3-psycho-social support via the sharing of experiential knowledge

B.1.4-creation of links to non-medical resources

B.2

B.2.1-complementary knowledge: orienting care towards a patient-centred model

B.2.2-a committed individual is a resource to add value to practices

B.2.2.1-creativity and innovation

B.2.2.2-support in promoting projects

B.2.3-changes in the caregiver-patient relationship

B.3

B.3.1-commitment on behalf of others is a constructive experience in relation to the illness

B.3.2-recognition and valorisation of experiential knowledge