APPENDIX

Development patient decision aid

The patient decision aid will be developed in collaboration with people with memory complaints, their significant others, and GPs, in line with the International Patient Decision Aid Standards (IPDAS).[42]The decision aid will be developed, implemented in general practice, and evaluated. This will be done in three phases; (1) exploration phase, (2) development phase, (3) evaluation phase (see Figure 1). The exploration and development of the patient decision aid partly run parallel to the inclusion of participants in the before group, rendering an optimal/efficient use of time.

Exploration phase

During the exploration phase, data will be collected and analysed as input for the patient decision aid. Interviews will be conducted with patients and their significant others that are recruited via a hospital-based memory clinic and with general practitioners. More information on these interviews and the inclusion procedure can be found in the next section. Furthermore, data from the practice-based research network Family Medicine Network (FaMe-net) of the Department of Primary and Community Care (ELG) at the Radboud University Medical Centre will be analysed to provide input for the development of the patient decision aid. FaMe-net consists of 11 Dutch general practices in three geographical regions (62.000 listed patients).[43,44] FaMe-net general practitioners systematically register data on the reason for encounter, diagnostic procedures, diagnoses, interventions, and referrals.[43,44] This data will be used to map the current decision-making process and diagnostic trajectory in general practice for people with memory complaints. Additionally, a systematic integrative review will be conducted about the preferences and needs of people with memory complaints, and their significant others, and GPs regarding the timing of dementia diagnosis.

Development phase

During the development phase, the patient decision aid will be developed with help of a steering group. This group will consist of people with memory complaints, caregivers, and general practitioners. During several workshop sessions their views, needs, and feedback will be incorporated on defining the scope of the patient decision aid. They will furthermore be asked to provide feedback on proposed prototypes by the research team. Prototypes will be adjusted according to their feedback. The final prototype will be pilot-tested with help of a small test panel. Its usability, language, and format will all be rated.

Evaluation phase

During the evaluation phase, the feasibility of the patient decision aid will be tested. Data to assess this feasibility will be collected in the after group of the before-after pilot study (see Figure 1). Also, online users of the patient decision aid will be asked to complete the Ottowa Acceptability Measures questionnaire. These users (N = 40-60) will be asked to rate the length, clarity, fairness, and helpfulness of the decision aid on a 4-or 5-box scale.

Study population and data collection to inform development patient decision-aid

Memory clinic group

People with memory complaints who were referred to a memory clinic for advanced diagnostic testing will be asked to participate in our study. These people will be recruited through the memory clinic of the MUMC + in Maastricht.

Inclusion procedure

Potential participants are asked to participate in the study before their first appointment at the memory clinic. A member of the treatment team of the memory clinic will inform potential participants about the study. If the participant is interested the researchers will contact the potential participant to provide detailed information about the study.

The following data from these participants will be used as input for the development of the patient decision aid;

1. Medical record

   Medical journals with the code 'memory complaint' and a possible referral letter to a memory clinic will be thematically analysed to assess the decision-making process.

2. Experiences and considerations in the decision-making process regarding the diagnostic assessment of memory complaints at their GP

   People with memory complaints and their significant others will be asked to participate in a semi-structured interview (by telephone).

General practitioners

General practitioners participating in the pilot study and the general practitioners of the people recruited via the hospital-based memory clinic will be asked to participate in a semi-structured interview (by telephone). Interviews will focus on their preferences, experiences, and opinions regarding an (early) diagnostic trajectory of memory complaints and the role of shared-decision making therein.

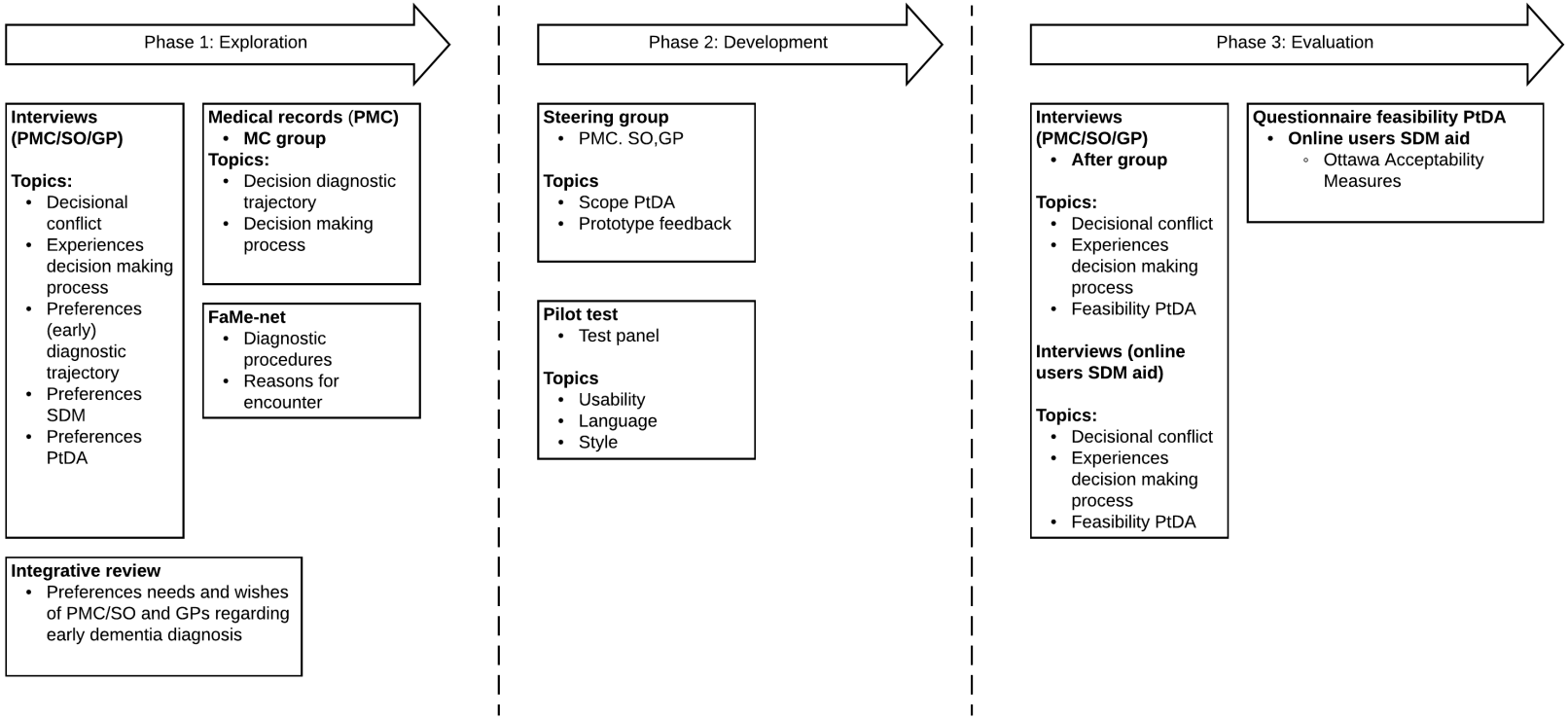

Figure 1. S-DeciDeD study overview.
Note. BG = Before Group, AG = After Group, PMC = Person with Memory Complaints, SO = Significant Other, GP = General Practitioner, PtDA = patient decision aid