### Table S1: Overview of ePRO systems with additional data

<table>
<thead>
<tr>
<th>Name of System</th>
<th>Country</th>
<th>No of patient users Population</th>
<th>Primary objective of system</th>
<th>In current use</th>
<th>System Measures and summary of measured domains or items</th>
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</thead>
<tbody>
<tr>
<td>ANZDATA SWIFT PROMs Module (1-5)</td>
<td>Australia</td>
<td>Collection via national registry 143 dialysis centres Target n=2400 In-centre haemodialysis</td>
<td>Improving symptom management associated with CKD and treatment Research</td>
<td>Yes – pilot study reported, Cluster RCT in progress 3 monthly for 12 months</td>
<td>SONG-HD fatigue measure (6) Three items that assess (1) the effect of fatigue on life participation, (2) tiredness, and (3) level of energy. IPOS-Renal (7) IPOS-Renal is a short measure, combining the most common symptoms (pain, shortness of breath, weakness, nausea, vomiting, poor appetite, constipation, sore/dry mouth, drowsiness, poor mobility, itching, difficulty sleeping, restless legs, changes in skin, diarrhoea) renal patients experience plus additional items from IPOS on concerns beyond symptoms, such as information needs, practical issues, family anxiety. EuroQol 5-Dimension 5-Level (EQ-5D-5L) (8) Measures quality of life across 5 domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension is scored on a 5-level severity ranking that ranges from &quot;no problems&quot; through &quot;extreme problems.&quot;</td>
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<tr>
<td>cPRO-Collaborate Kidney Care (9)</td>
<td>United States of America Single renal unit n= approximately 350 CKD Stages 1-3 CKD Stages 4-5 pre dialysis</td>
<td>Improving symptom management associated with CKD, Patient-provider communication Community/general practice/hospital clinic</td>
<td>Yes – clinical demonstration model 72 hours prior to clinical assessment visit and 3 monthly FU</td>
<td></td>
<td>PROMIS and FACIT measures (9) Items from PROMIS and FACIT to measure: Health perception and global health, fatigue, anxiety, pain, depression, physical function, shortness of breath, urinary frequency, oedema, Appetite, itching, side effect bother, shared decision-making, self-efficacy managing treatments, self-efficacy managing symptoms, treatment satisfaction</td>
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<tr>
<td>Study</td>
<td>Region</td>
<td>Methodology</td>
<td>Instrumentation</td>
<td>Data Collection</td>
<td>Notes</td>
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<td>Cambian (ePRO-KIDNEY) (10-16)</td>
<td>Canada Regional</td>
<td>Enhance and support person centred kidney care via research program on ePRO use and implementation</td>
<td>No – platform used within reported research projects Prior to clinical assessment Set time point 3 monthly</td>
<td><strong>Patient Assessment of Care for Chronic Conditions-20 questionnaire</strong> (PACIC-20) (17, 18) <strong>Kidney Disease Quality of Life-36 (KDQOL-36)</strong> (19, 20) <strong>Edmonton Symptom Assessment System renal</strong> (ESAS-R RENAL) (21) <strong>EQ-5D-5L</strong> (8)</td>
<td><strong>Patient Assessment of Chronic Illness Care (PACIC) assesses the implementation of the chronic care model (CCM) from the patient perspective that focuses on the receipt of patient-centred care and self-management behaviours, this 20 item instrument has five pre-defined domains: patient activation (3 items), delivery system/practice design (3 items), goal setting/tailoring (5 items)</strong> (\text{Based on the KDQOL-SF™. It includes the SF-12 as generic core plus the burden of kidney disease, symptoms/problems of kidney disease, and effects of kidney disease scales from the KDQOL-SF™v1.3.36 items, and two cores: the SF-12 (i.e., generic QOL) and the disease-specific core. The generic core consists of two domains: the physical component summary (PCS) [6 items] and the Mental Component Summary (MCS) [6 items]. The disease-specific core consists of 24 items with 3 domains: symptoms and problems (12 items), burden of kidney disease (4 items) and effects of kidney disease (8 items).** (\text{ESAS-R Renal 10 items (symptoms - pain, tiredness, drowsiness, nausea, lack of appetite, shortness of breath, depression, anxiety, well-being, other problem - Can be modified to include Restless Legs Syndrome single question, RLS defined as 'uncontrollable urge to move your legs')** (\text{EQ-5D-5L} ) <strong>As above</strong></td>
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<td>OPT-ePRO (22-25)</td>
<td>United Kingdom</td>
<td>Improving symptom management associated with CKD and treatment, Research</td>
<td>No – pilot study reported Prior to clinical assessment</td>
<td><strong>POS-S-RENAL</strong> (26) <strong>POS-S can also be used on its own, if only a symptom assessment is required, POS-S is available as a renal card - this version assesses 17 symptoms (symptoms (pain, shortness of breath, weakness, nausea, vomiting, poor appetite, constipation, sore/dry mouth, drowsiness, poor mobility, itching, difficulty sleeping, restless legs, changes in skin, diarrhoea, feeling anxious, feeling depressed), plus open fields to list main symptoms</strong></td>
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<tr>
<td>Study</td>
<td>Country</td>
<td>Setting</td>
<td>CKD Stages</td>
<td>Health Outcomes</td>
<td>EQ-5D-5L</td>
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<td>Penguin (Clevert Ltd) (no published data)</td>
<td>United Kingdom</td>
<td>Single renal unit Pilot n=5 Transplant</td>
<td>CKD Stages 4-5 pre dialysis</td>
<td>Facilitate patient-provider communication Secondary care – aim is to complete from home</td>
<td>Yes - Research pilot in progress Prior to clinical assessment visit or annual review</td>
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<td>RePROM (27-31)</td>
<td>United Kingdom</td>
<td>Single renal unit n=24 CKD Stages 4-5 pre dialysis</td>
<td>Improving symptom management associated with CKD and treatment Secondary care (hospital clinic), home</td>
<td>No – pilot study reported. Monthly reporting</td>
<td>New study specific measure – RePROM (27) Items on fatigue; shortness of breath; loss of appetite; nausea or vomiting; itchiness or dry skin; pain; problems with fistula; faintness or dizziness; difficulty sleeping; restless legs; diarrhoea and ankle swelling. The questionnaire also includes an open text item</td>
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<tr>
<td>Unnamed System 1 (32)</td>
<td>Canada</td>
<td>Single renal unit n=approx. 60 In-centre HD, Transplant</td>
<td>Improving symptom management associated with CKD Research Secondary care (hospital clinic), Dialysis centre</td>
<td>No – in development: pre-defined set time-points within research protocol</td>
<td>PROMIS CATs (33) (unspecified) Previous pilot study to assess usability collected data from several measures (32)</td>
</tr>
<tr>
<td>Study</td>
<td>Country/Regional Setting</td>
<td>Symptom Management Focus</td>
<td>Study Design/Details</td>
<td>PROs Used</td>
<td>Additional Information</td>
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<tr>
<td>‘Your symptoms matter’ (34, 35)</td>
<td>Canada 1 provincial region n=1459 In-centre HD</td>
<td>Improving symptom management associated with CKD and treatment Secondary Care (Hospital clinic), Dialysis Centre</td>
<td>Yes – pilot study reported Every 4-6 weeks</td>
<td>ESAS-r: Renal (21)</td>
<td>As above</td>
</tr>
<tr>
<td>Ambuflex (PRO-KID) Non-inferiority pragmatic randomised controlled trial evaluating incorporating Ambuflex platform where clinicians review responses) (36-41)</td>
<td>Denmark Ambuflex – National PRO-KID – one hospital renal unit Ambuflex CKD Stages 4-5 pre dialysis, Conservative Care PRO-KID CKD Stages 4-5 pre dialysis</td>
<td>Improving symptom management associated with CKD Patient-provider communication</td>
<td>Ambuflex Home PRO-KID - home</td>
<td>Ambuflex - Yes every 3rd month. PRO and laboratory tests inform clinicians whether the patient needs contact with outpatient clinic (PRO-KID – trial in progress, every 3 months)</td>
<td>Ambuflex 27 item Renal Disease questionnaire (37)L including domains on kidney disease (Lack of appetite, food aversion, feeling of unease, nausea, vomiting, itchy skin, shortness of breath, swollen legs, dizziness, difficulty remembering, difficulty concentrating, restless legs, feeling tired, bodily pain, limited in regular daily activities, constipation, diarrhoea, nocturnal urination, trouble sleeping, worried about future health, difficulties remembering to take medication) and Quality of life (2 items), free text space for 3 topics to would like to discuss PRO-KID 1. Renal-specific domains, items from • KDQOL-SF • EORTC • SF-GH1 • Need/wish for consultation • Free textbox 2. Additional research PROs not available to clinicians administered at baseline, 3, 6 and 18 months (36)</td>
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<tr>
<td>SMaRRT-HD™ (42, 43)</td>
<td>United States of America Regional (clinic and dialysis unit) N=62 In-centre HD</td>
<td>Improving symptom management associated with treatment</td>
<td>Dialysis Centre (Clinic + treatment area)</td>
<td>Unknown – feasibility study reported Twice monthly administered during first 30 minutes of HD (recall period of the last HD treatment for each symptom</td>
<td>New Study specific measure - SMaRRT-HD™ (42) Symptom Monitoring on Renal Replacement Therapy-Hemodialysis (SMaRRT-HD™) is a 14-item PROM intended for use in hemodialysis patents. SMaRRT-HD™ uses a single treatment recall period and a 5-point Likert scale to assess symptom severity across 13 Symptoms (12 specific: Cramping Feeling washed out, Light headedness, Restless legs, Nausea, Vomiting, Headache, Tingling Thirst, Shortness of breath Chest pain, Heart palpitations Itching, 1 free text type in); time to recovery question</td>
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<tr>
<td>Study</td>
<td>Country</td>
<td>Setting</td>
<td>Sample Size</td>
<td>Care Setting</td>
<td>Participated in Survey</td>
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<td>Derby Evaluation of Illness (44)</td>
<td>United Kingdom</td>
<td>Single renal unit</td>
<td>n=43 (19 HD, 5 PD, and 19 CKD)</td>
<td>CKD stages 4/5 predialysis, in-centre HD, PD</td>
<td>Did not participate in survey</td>
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<td>EMPATHY study (45-48)</td>
<td>Canada</td>
<td>Three provincial regions</td>
<td>n=approx. 3,000</td>
<td>In-centre HD</td>
<td>Did not participate in survey</td>
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<tr>
<td>K-Pal (49)</td>
<td>United States of America</td>
<td>Single dialysis unit</td>
<td>n=22</td>
<td>Patient’s ≥60 years of age with ESRD on HD</td>
<td>Did not participate in survey</td>
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<tr>
<td>Study</td>
<td>Country</td>
<td>Study Population</td>
<td>Survey</td>
<td>Analysis</td>
<td>Notes</td>
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<td>eNephro (54)</td>
<td>France</td>
<td>Five Hospitals, 3 not for profit providers</td>
<td>GAD-7, DSI, KDQOL-36</td>
<td>Patient assessed presence of symptoms</td>
<td>Did not participate in survey, Home tele-monitoring, Patient assessed symptoms reported every 3 days, PROs to assess study outcomes: KDQOL-36 (19, 20), Hospitalization Anxiety Depression Scale (HADS) (55), ReTransQoL (for transplant patients) (56)</td>
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<td>Dutch Renal Registry (57-59)</td>
<td>The Netherlands</td>
<td>Collection via national registry pilot study in 16 centres</td>
<td>GAD-7, DSI, KDQOL-36</td>
<td>Dialysis Symptom Index (DSI) (53)</td>
<td>Did not participate in the survey, Home, During dialysis session (precise timing not specified), Yes – part of development of national registry of PROMs Baseline, 3 &amp; 6 months during study period, SF-12 (60), A 45-item measure designed to assess QOL in renal transplant patients. There are 5 dimensions: (i) physical health (ii) social functioning (iii) medical care (iv) treatment (v) fear of losing graft</td>
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</table>

**Questionnaires:**

- **Generalized Anxiety Disorder 7 Item Survey (GAD-7) (52)**
  - 7 item questionnaire exploring generalised anxiety

- **Dialysis Symptom Index (DSI) (53)**
  - A 30-item measure designed to assess symptom prevalence and severity in patients on haemodialysis. 21 items relate to physical symptoms, 9 to emotional symptoms, plus open-ended question to report additional symptoms

- **Kidney Disease Quality of Life (KDQOL-36) (19, 20)**
  - As above

- **ReTransQoL (for transplant patients) (56)**
  - A 45-item measure designed to assess QOL in renal transplant patients. There are 5 dimensions: (i) physical health (ii) social functioning (iii) medical care (iv) treatment (v) fear of losing graft

**Surveys for hospitalization:**

- **Hospitalization Anxiety Depression Scale (HADS) (55)**
  - 14 questions in total (seven covering depression and seven covering anxiety).

**Surveys for transplantation:**

- **SF-12 (60)**
  - A generic HRQOL questionnaire: 12 items to measure HRQOL
    - Domains: Physical functioning (PF) (2 items), Role physical (RP) (2 items), Bodily pain (BP) (1 item), General health (GH) (1 item) Vitality (VT) (1 item) Social functioning (SF) (1 item) Role emotional (RE) (2 items) Mental health (MH) (2 items)
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