# Section 12

# Next steps

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At the end of each PEEK study, CCDR identifies three key areas that, if improved, would significantly increase the quality of life and/or the ability for individuals to better manage their own health.

In relation to this community, these three areas are:

1. **Information:** This is a patient group that is ready for information from the point of diagnosis, however decision-making about treatments is complex and there was a lack of clarity about disease progression and prognosis. This patient population would benefit from more detailed and accessible information about treatment options and discussions about what to expect in the future. This could be aided by the documentation of holistic treatment and care plans with regular revisions.

2. **Support:** A common theme was the need for specialised support and care, ideally via telephone. This patient population would benefit from a central, dedicated telehealth nurse navigator that can link patients and families to the specific services they need, based on their unique presentation of symptoms. This includes access to mental health support as close to half of the participants noted depression and/or anxiety and the largest gap in information was about psychological/social support.

3. **Quality of life:** This cohort valued the ability to exercise as a way to maintain their physical and mental health, while the biggest negative impact on quality of life was a reduced capacity for physical activity. This patient population would benefit from targeted physical programs that allow them to exercise within their limitations. This would also have positive social and psychological benefits.

### 2020 Amyloidosis

Data collected in this PEEK study also provides a basis on which future interventions and public health initiatives can be based. Some of the 2020 metrics that the sector can work together to improve upon are provided in Table 12.1

**Table 12.1 Amyloidosis 2020 Metrics**

| Measure | Detail | Mean | Median |
|---|---|---|---|
| **Baseline health (SF36)** | Physical functioning | 53.47 | 52.50 |
| | Role functioning/physical | 37.50 | 25.00 |
| | Role functioning/emotional | 62.04 | 66.67 |
| | Energy/fatigue* | 43.33 | 45.00 |
| | Emotional well-being | 72.44 | 76.00 |
| | Social functioning | 60.76 | 62.50 |
| | Pain * | 59.58 | 55.00 |
| | General health* | 46.81 | 45.00 |
| | Health change | 40.28 | 37.50 |
| **Knowledge of condition and treatments (Partners in Health)** | Knowledge | 27.36 | 28.00 |
| | Coping | 17.68 | 18.50 |
| | Recognition and management of symptoms * | 20.68 | 21.00 |
| | Adherence to treatment | 15.32 | 16.00 |
| | Total score* | 81.04 | 82.00 |
| **Care coordination scale** | Communication* | 42.17 | 42.00 |
| | Navigation* | 27.56 | 27.00 |
| | Total score* | 69.72 | 72.00 |
| | Care coordination global measure | 7.92 | 8.00 |
| | Quality of care global measure | 8.44 | 9.00 |
| **Fear of progression** | Total Score * | 33.19 | 31.50 |
| | | **Percent** | |
| **Accessed My Health Record** | - | 39.29 | - |
| **Participants that had discussions about biomarkers/genetic tests** | - | 39.29 | - |