

INTRODUCTION

- Well-differentiated neuroendocrine neoplasms (NENs) are increasingly viewed as chronic diseases, as a result of more effective treatments and procedures.
- As with any life changing events, patient and family transition to a new "normal" requires attitudinal adjustments.
- The Intensive Personalized Program for Daily Living with NENs is a pilot program transitioning patients and their primary carer to a new "normal".

AIM

- To evaluate long term QoL implications of attitudinal and nutritional changes of NEN patients and their carer using an intensive interventional program.

METHODS

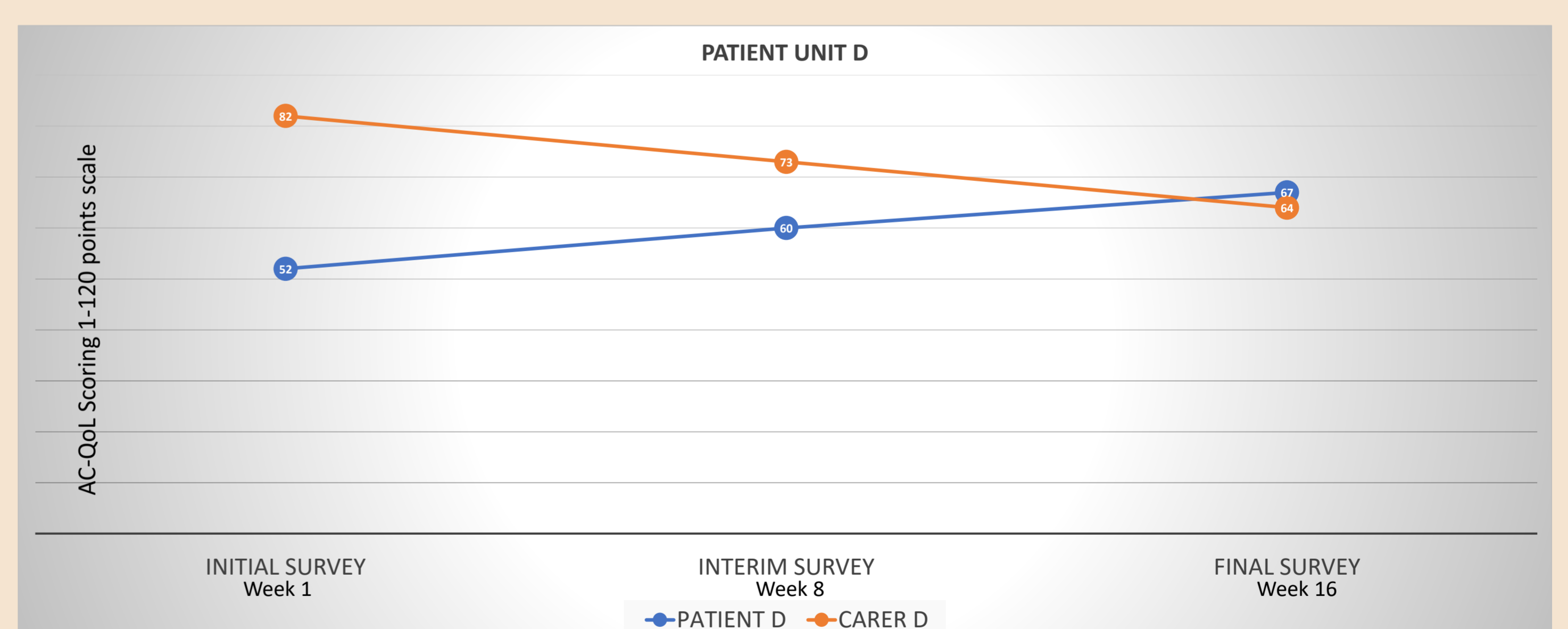
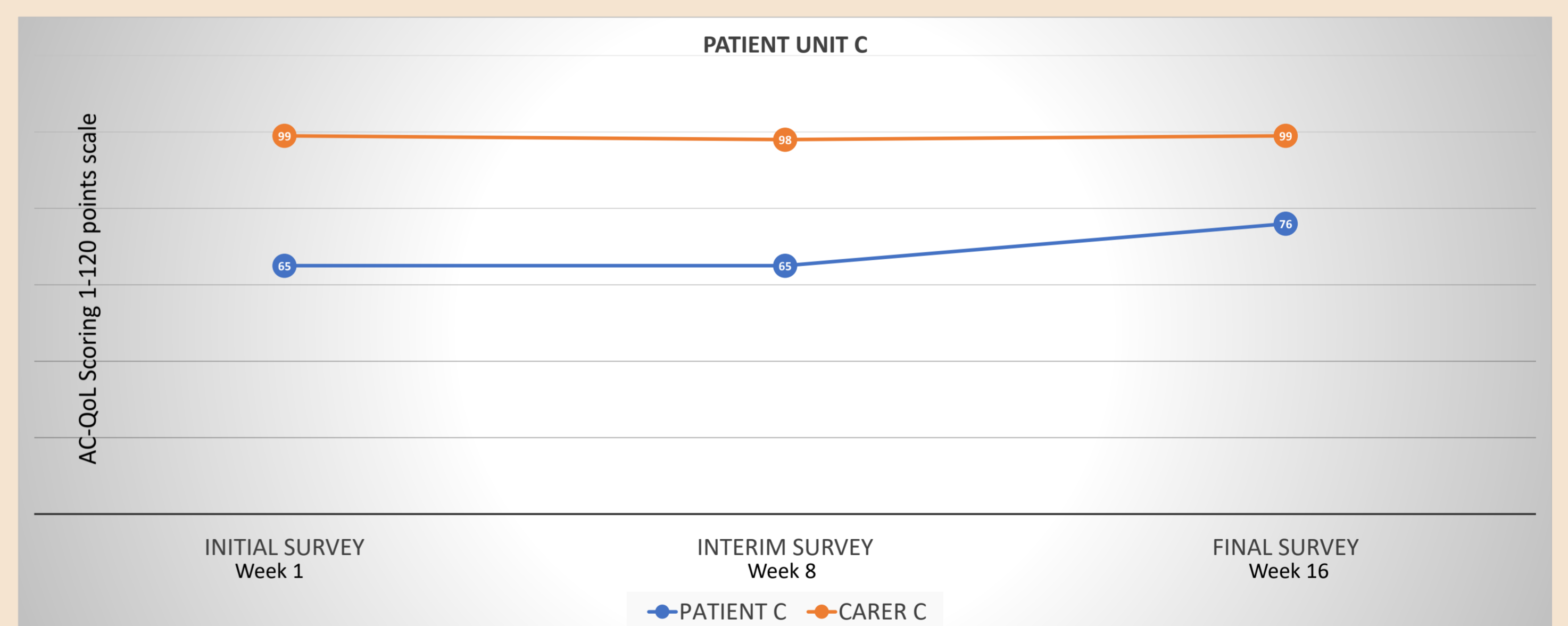
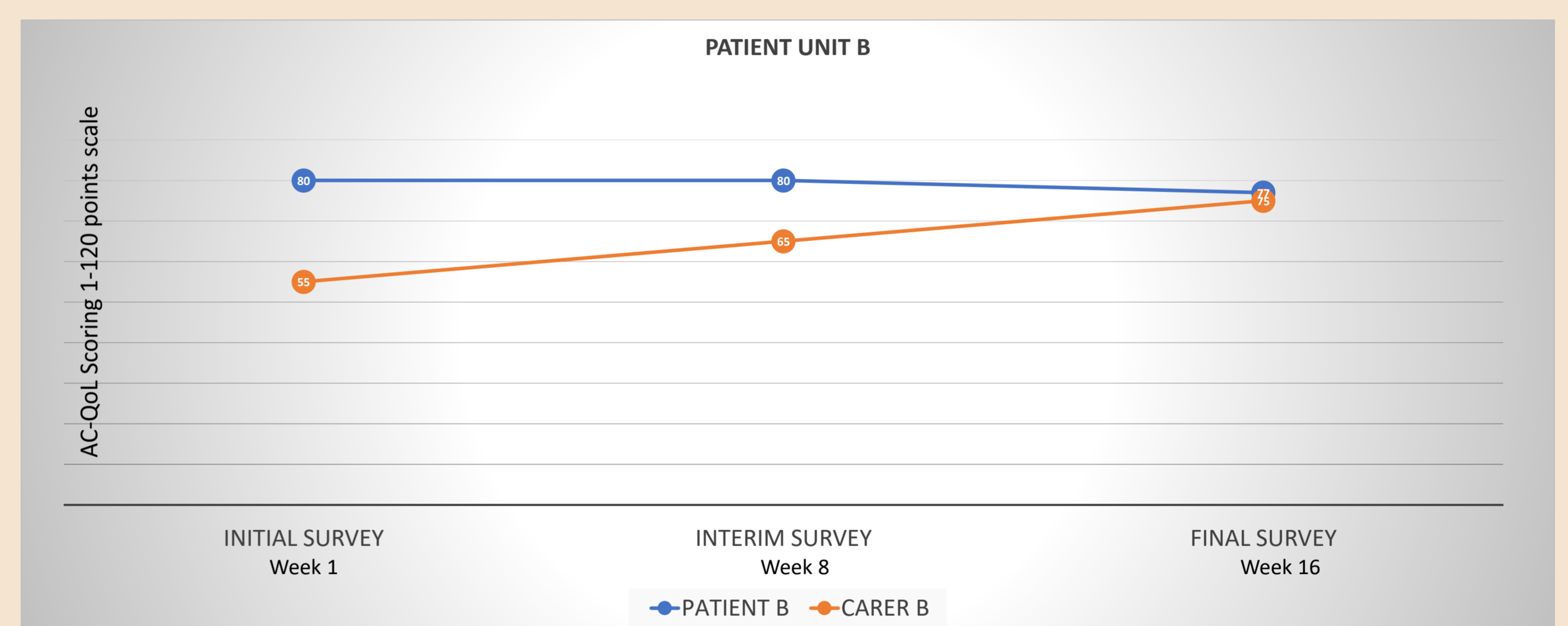
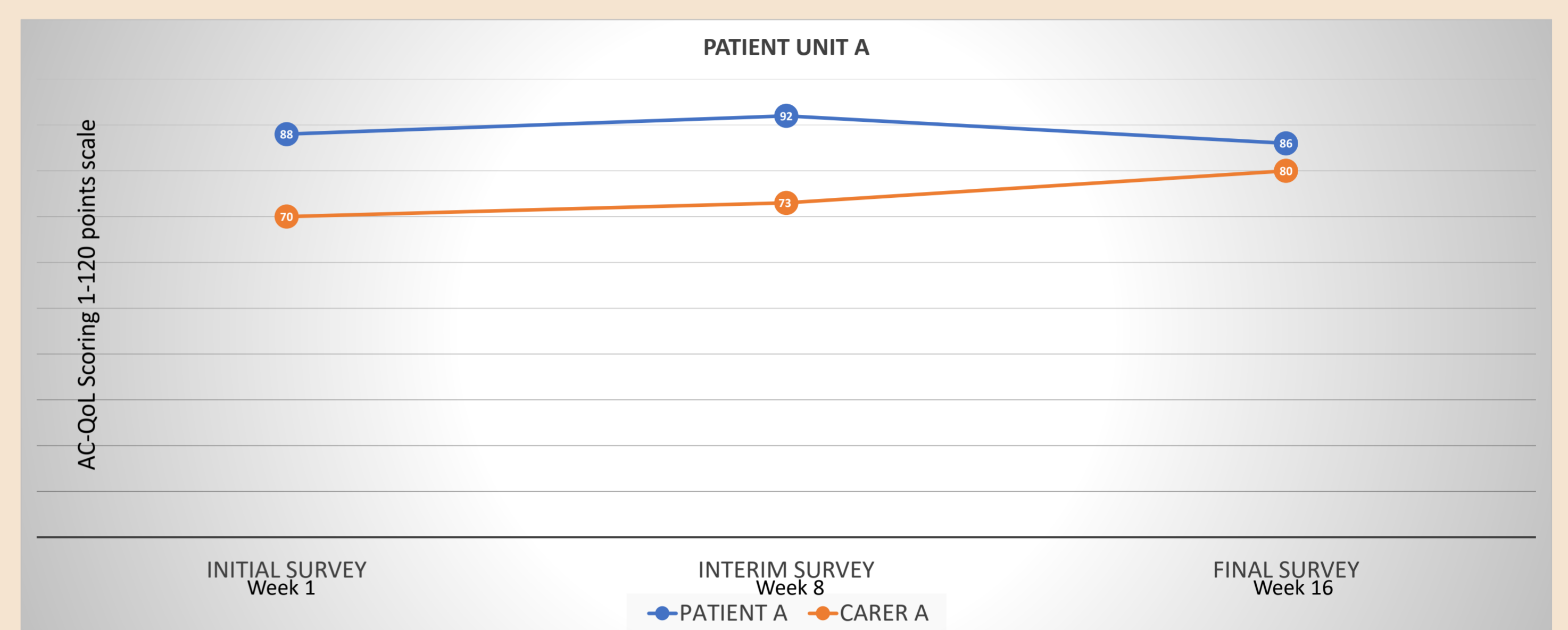
- Roles:**
 - Program / Workshop Coach
 - NEN Dietitian
 - Scientific Advisor
 - Nutritionist
- Screening Criteria:**
 - Exclusion:** End stage renal failure; parenteral nutrition; uncontrolled psychiatric illness; patients without a personal carer e.g. spouse; age <18yo; pregnancy or lactation
 - Inclusion:** Israeli NEN patients together with the carer ("Patient Unit") who volunteered for the program, diagnosed with gastroenteropancreatic (GEP) or lung NENs, with or without syndromes.
- Process:** (See "PEBBLE" Program Map)
 - The Patient Units attended a three day dedicated residential workshop called "PEBBLE", July 9-11, 2019.
 - The Patient Units attended three video interviews with the NEN Dietitian followed by individualized recommendations.
 - The purpose of the workshop is to teach attitudinal techniques to live with Cancer as a Chronic Disease.
 - Techniques include CBT, NLP and Mindfulness.

RESULTS

- Four patients with GEP-NENs completed adapted adult patient & carer QoL questionnaires, and attended an initial virtual consultation with their carer, coach, and NEN Dietitian.
- After completing a three day interactive workshop, four NENs patient-carer couples were followed by a clinical NEN Dietitian and the workshop coach.
- Patient reported outcomes using adapted adult patient and carer QoL questionnaires were analysed¹. An adapted research instrument based on the Carer Scoring Manual was also used for Patient Scoring.
- At six months follow-up, two patients retained the initial QoL score and two showed 17% & 29% score improvement. Carer scoring showed one stable, two improvement of 14% & 28%, and one showed a drop of 22%.
- All patients showed increased eating discipline and autonomy.
- Carers reported increased independence to continue their personal activities.
- Additionally, Patient Units documented increased understanding of each other's challenges, decreased expectations, and increased cooperation. (See figures).

"PEBBLE" PROGRAM MAP

WEEK 1	WEEK 4	WEEK 8	WEEK 16
BLOOD WORK SUBMISSION BY PATIENT	RESIDENTIAL "PEBBLE" WORKSHOP 	NUTRITION FINE-TUNING PER COUPLE	BLOOD WORK SUBMISSION BY PATIENT
NUTRITION EVALUATION AND INITIAL RECOMMENDATIONS		ONE-ON-ONE INTERVIEW WITH COACH FOR PATIENT AND CARER	FINAL NUTRITION RECOMMENDATIONS PER COUPLE
ONE-ON-ONE INTERVIEW WITH COACH FOR PATIENT AND CARER			ONE-ON-ONE INTERVIEW WITH COACH FOR PATIENT AND CARER



CONCLUSIONS

- Preliminary data provide important insights on the major role of such an intensive personalized program in transitioning patients and carers to a "new normal".
- Additional workshops/larger number of participants will help fine tune the effectiveness of this program for improving QoL of NEN patients and their carer.

Reference:

- Elwick, H., Joseph, S., & Becker, F (2010) Manual for the Adult Carer Quality of Life Questionnaire (AC-QoL), London: The Princess Press Royal Trust for Carers.