Introduction: It can be estimated that there are approximately 7000 people living with a stoma in the Republic of Ireland with approximately 1400 new stoma patients each year. This survey was designed to help us understand how people in Ireland with a stoma feel about their life and what issues, if any, they were having.

Methodology: The survey was designed using the Modified City of Hope QoL ostomy questionnaire. Questions included basic demographics and adjustment questions and those related to physical, psychological, social and spiritual well-being.

Subjects and Setting: All 494 members of the Ileostomy Association (IA) in Ireland were posted the questionnaire. A further 101 ostomates were also sent the questionnaire by 5 participating Stoma Care Nurses (SCN’s). Full anonymity was assured. Of the potential 595 respondents, 256 people replied to the survey. This gave a response rate of 43% and a margin of error of 4.62 with a confidence interval of 95%.

Results: The answers were analysed and found to be consistent with other studies. This would indicate that the quality of life of people in Ireland with a stoma is within the normal limits and similar to the general population. However, it took 45% of people over 6 months to come to terms with their stoma care. A large amount of information was obtained from the questionnaire which is impossible to convey here so five of the more interesting results have been chosen.

1. Sexual Function

Findings: 46% of those who replied to the survey were not followed up at home by a SCN, despite over 95% of those who were finding it helpful.

Discussion: Only 21 men gave cancer as their reason for having a stoma and only 32 of the 101 have a colostomy and 1 a urostomy.

2. Mental Health

Findings: 29% of respondents feel they are moderately to severely depressed. This is higher than the national average of 10%.

Discussion: This may be due to the stigma of mental health in that people are reluctant to come forward to the medical profession with their concerns but feel able to reply to an anonymous survey more easily. The role of the community SCN has been shown to be important in the reduction of psychological and social problems in ostomates.

3. Patient Information

Findings: Table 1 shows that most people who answered the survey have to adjust both their diet and style of clothing. Furthermore over 27% of people responded they avoid eating vegetables and 32% stating they do not eat fruit.

Discussion: Much of the information we give patients says that most people get back to eating their normal diet and wearing their normal clothes. These results suggest that is not the case, with over half disagreeing.

4. Stoma Related Problems

Findings: Problems with peristomal skin have been well-documented. Figures 3 and 4 show that 34% of those who answered have problems with their skin with the same number having leakage issues.

Discussion: This is of concern, especially as most of the ostomates in the study have had their stomas for a long time. They may think of it as normal or may not have links to an SCN. It demonstrates the need for routine, regular following up of ostomates.

5. Community Stoma care

Findings: The results show that 46% of those who replied to the survey were not followed up at home by a SCN, despite over 95% of those who were finding it helpful.

Discussion: Shorter hospital stays times can reduce the education a patient receives on the prevention of stoma complications and it is not until a person is at home that the full impact of having a stoma is known. The need for home follow up is well documented both to benefit the patient and reduce costs to the health system. However, almost half of the people in this survey had not been given this service.

References: