How patients can improve health care

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INTRODUCTION

I am delighted to welcome readers to our first edition of 2018 in our third year of publication. We are honoured to partner with The Point of Care Foundation on a special edition on “Patients as co-designers of interventions to improve the quality of their care”.

This edition is anchored by an editorial from Joanna Goodrich, Head of Evidence and Learning at The Point of Care Foundation. She sets the scene by pointing out that evidence-based co-design (EBCD) is a method for improving the experience patients (and their families) have: the first phase involves gathering patients’ experiences, and the second is to re-design the experiences together. The Point of Care Foundation has been a pioneer in this methodology and created an EBCD toolkit and resources used worldwide.

Many of the contributions build on this theme with specific examples in diverse settings, myriad conditions and in different countries. The theme of this edition is consistent with the trend worldwide to include and act on the patient perspective as one of the foundations to achieving better outcomes in health care. This trend is more than a desire to be seen to be “user-friendly” among care providers—it is the smart response to increasingly empowered and informed users of services.

Three trends are critical to the future of the service provider. Firstly, people expect, if not demand, that their service providers (health care or otherwise) be responsive to their ideas, concerns, and expectation. This expectation is prevalent now more than ever, and especially in countries where there is a large co-payment factor in the remuneration for services. With money changing hands it is no longer acceptable to offer poor access, tolerate shoddy infrastructure, incorporate avoidable delays, condone poor communication, and overlook lack of consultation on the choices available to the consumer. Consumers’ choices require consideration of the risks and benefits presented in a digestible format.

Secondly, patients are much more informed and connected via social media. The notion of the provider as the sole custodian of knowledge limits the scope to achieve best results by failing to harness the wealth of information and support that already exists and is accessible to those who seek it. Connected patients communicate with each other. Unsatisfactory services are soon drawn to the attention of others at the click of mouse.

Finally, the providers of healthcare and wellness services are burgeoning; there’s increasing competition and different healthcare disciplines are experiencing changing scopes of practice. Nurse, pharmacists, and allied health practitioners are often the healthcare professional that the patient spends most time with on their healthcare journey. In some cases, the person that the “patient” has most to learn from is another person with the same condition. We are also seeing more direct access to “specialists”, practitioners with very specialized skills in advising on lifestyle change but in many countries also medical practitioners with specialist technical expertise;
and more direct marketing to the consumer of all things, including drugs that require prescriptions.

These three elements comprise the reality in which we operate or will operate because the genie is out of the lamp. There is no returning to the world in which the “expert” (ie, the physician) knew best and the “user” (ie, patient or consumer) had to accept whatever was offered and be thankful for it. The internet has changed everything at a pace faster than most of us had anticipated. Those providers who embrace these trends are set to benefit from the wealth of experience and feedback at their disposal.

We are delighted to share the experience of many who have kindly submitted their ideas for dissemination. We acknowledge The Point of Care Foundation, and especially Joanna Goodrich, for tirelessly working to bring you this special edition. We look forward to bring you the next special edition on “Innovative ways of gathering feedback from patients to inform design”, led by Bev Fitzsimmons, Head of Improvement at The Point of Care Foundation. Most of all, we thank the contributors and readers of the journal for providing the impetus to continue to develop a forum on patient experience design.