

Open Design and Cystic Fibrosis: Enabling Participation in the Design Process

Keywords: open design, cystic fibrosis, participatory design, chronic disease

This paper describes the results of a project to collaboratively design a medication dispenser using open design. This work explores the benefits of open design (open-source design) in the conception (and development) of medical products. Described here is the first attempt to tackle some of the issues facing the implementation of open design in the field of medical product design where a recognised move to 'open' working practices & innovation is needed (Barrett, 2010); as is the imperative to more fully include users in the development process (Karlsson et al., 2011; Martin & Barnett, 2012; Money et al., 2011; Owens et al., 2011; Shah, Robinson, & AlShawi, 2009). There are moral and pragmatic reasons to include people in the design process (Carroll & Rosson, 2007), especially true for medical products. Presented are the results of online collaborative design work with a geographically diffuse group of people with Cystic Fibrosis; the prototype, and the open design implementation developed and used.



Figure 1: Medication dispenser; one of the open-source medical products developed

The project prototyped a wholly virtual meeting of people, empowering them to conceive and develop their own products based on their own lived experience of Cystic Fibrosis. The project involved the development of a community of people with Cystic Fibrosis, supported through tools and online workshops with a designer,

within an Action Research methodology. It is expected that open design has a positive contribution to make in the field of medical product design more widely, despite the very real questions surrounding its implementation. This research demonstrates the benefit open design can bring to (in particular) early stage concept generation, as well as continual evaluation and the fostering of innovation by leveraging the knowledge and action of lead users (Von Hippel, 1986). However, also included is an analysis of the regulatory, implementation, and economic factors that pose challenges.

References

- Carroll, J., & Rosson, M. (2007). Participatory design in community informatics. *Design Studies*, 28(3), 243–261. doi:10.1016/j.destud.2007.02.007
- Karlsson, I. C. M., Engelbrektsson, P., Larsson, L. E., Pareto, L., Snis, U. L., Berndtsson, B., & Svensson, L. (2011). Use-centred design of medical and healthcare technology: a pilot study of field tests as a development tool. *International Journal of Biomedical Engineering and Technology*, 5(1), 11. doi:10.1504/IJBET.2011.038470
- Martin, J. L., & Barnett, J. (2012). Integrating the results of user research into medical device development: insights from a case study. *BMC medical informatics and decision making*, 12, 74. doi:10.1186/1472-6947-12-74
- Money, A. G., Barnett, J., Kuljis, J., Craven, M. P., Martin, J. L., & Young, T. (2011). The role of the user within the medical device design and development process: medical device manufacturers' perspectives. *BMC medical informatics and decision making*, 11(1), 15. doi:10.1186/1472-6947-11-15
- Owens, C., Farrand, P., Darvill, R., Emmens, T., Hewis, E., & Aitken, P. (2011). Involving service users in intervention design: a participatory approach to developing a text-messaging intervention to reduce repetition of self-harm. *Health expectations: an international journal of public participation in health care and health policy*, 14(3), 285–95. doi:10.1111/j.1369-7625.2010.00623.x
- Shah, S. G. S., Robinson, I., & AlShawi, S. (2009). Developing medical device technologies from users' perspectives: a theoretical framework for involving users in the development process. *International journal of technology assessment in health care*, 25(4), 514–21. doi:10.1017/S0266462309990328
- Von Hippel, E. (1986). Lead Users: A Source of Novel Product Concepts. *Management Science*, 32(7), 791–805. doi:10.1287/mnsc.32.7.791