My Health Book is a initiative that challenges the notion that the health providers should be the carriers of health data, and that the patient should play only a peripheral role in the information flow pertaining their care. Objective: To derive guidelines for designing a patient controlled health information system that can gather, organize and use patient data. Methodology: Action design research is employed in two iterations to derive guidelines in a patient-patient health data ensemble. Method: Create a prototype that provides functionality for storing and sharing personal patient records using a web system and an iPhone app. The app is used to take snapshots of printouts from a health care provider, and is stored in 5 pre-set immutable categories, which can be accessed online, displayed at a consultation, or shared remotely using a one time code system. Evaluation is conducted on the prototype in two stages, first by means of a workshop, second by focused interviews with test users. Results: Support is found for using existing output channels from the Norwegian health information infrastructure in the form of paper printouts, appropriated by the app and mobile phone camera. Adversely, the idea of remotely sharing health documents organized in a patient controlled solution has met resistance and has proved to be problematic. Patient control is identified as being dependant on empowering technical abilities. Targeting the IS towards two audiences with conflicting interests negate control through the introduction of tensions that manifest in the technical implementation. Three design guidelines are produced for the role, implementation and look & feel of patient controlled systems.

My Health Book is a initiative that challenges the notion that the health providers should be the carriers of health data, and that the patient should play only a peripheral role in the information flow pertaining their care. Objective: To derive guidelines for designing a patient controlled health information system that can gather, organize and use patient data. Methodology: Action design research is employed in two iterations to derive guidelines in a patient-patient health data ensemble. Method: Create a prototype that provides functionality for storing and sharing personal patient records using a web system and an iPhone app. The app is used to take snapshots of printouts from a health care provider, and is stored in 5 pre-set immutable categories, which can be accessed online, displayed at a consultation, or shared remotely using a one time code system. Evaluation is conducted on the prototype in two stages, first by means of a workshop, second by focused interviews with test users. Results: Support is found for using existing output channels from the Norwegian health information infrastructure in the form of paper printouts, appropriated by the app and mobile phone camera. Adversely, the idea of remotely sharing health documents organized in a patient controlled solution has met resistance and has proved to be problematic. Patient control is identified as being dependant on empowering technical abilities. Targeting the IS towards two audiences with conflicting interests negate control through the introduction of tensions that manifest in the technical implementation. Three design guidelines are produced for the role, implementation and look & feel of patient controlled systems.