



Data Storage Procedures:

Take a Pain Check Foundation stores all sensitive data, including data shared by Arthritis Society Canada, on a secure NAS drive. No sensitive data is ever shared on Outlook or external platforms.

Files related to the Backpack Program may only be accessed by authorized staff who require the information to perform their job responsibilities. Access permissions and security controls must be reviewed regularly to ensure continued compliance with this requirement.

All data must be encrypted both at rest and in transit. Appropriate encryption safeguards must be applied whenever data is stored, accessed, transferred, or shared between parties. Each party is responsible for ensuring that the data it transmits is encrypted using secure and approved methods throughout the transmission process.

Information Practices: Take a Pain Check uses information gained from the Backpack Program to improve engagement with patients in several ways...

1. *Email of patients:* As an organization, we use email addresses to contact patients to offer particular programs, services, & gain valuable feedback on the impact of the backpack program to improve the program for the future.
2. *Provincial/Municipal information:* By knowing which provinces patients are coming from, TAPC can align our campaigns and programs to feature more heavily in provinces with more interest in services or put more resources into provinces with few service offerings. As a youth-based organization, we must have a certain level of data sovereignty to assess what specific data points mean for our clients & be able to do so on our own timeline.
3. *Age of Patient:* This information helps TAPC identify which programs and resources are most appropriate for each individual, as many of our initiatives are designed for specific age groups. Understanding the age distribution of applicants allows us to better target outreach efforts, establish appropriate age criteria for programs and support groups, facilitate age-appropriate peer connections, and enhance initiatives such as the Backpack Program to better meet participants' needs.



4. *Referring Rheumatologist's name*: Important to running Take a Pain Check's programming, the rheumatologist's name helps define strategic priorities by linking each registration to a referring rheumatologist. By linking patients to a rheumatologist/clinic in our records, we analyze geographic areas in need of further program outreach. This

analysis helps us tailor program outreach & material to relevant communities. Without it, the organization is forced into generalizing outreach efforts to all rheumatologists, which inefficiently wastes resources. With said data points, Rheumatologists with a history of recommending the backpack program can then be contacted via publicly available data to receive information about TAPC programming & services that would fit their patients' needs. Both patients & rheumatologists will be made aware that their information can be used in any way, with the ability to opt in and out.

5. *Diagnosis of patient*: Collecting diagnostic data also enables TAPC to provide more relevant and tailored support by connecting patients with programs, resources, and opportunities that best align with their specific condition and lived experience.
6. While the majority of information collected is used exclusively to administer and operate the Teen Backpack Program, certain non-public insights gained through participation may also help inform outreach planning and strategic priorities across other TAPC initiatives, including the Scholarship Program. Participants in the Teen Backpack Program are considered members of the broader TAPC community. As part of our community engagement efforts, we may use contact and program participation information to identify and share opportunities, resources, events, and programs that may be relevant to participants and their families. For example, in 2026, TAPC shared information about the STEM Without Limits Scholarship Program with members of the TAPC community, including patients, families, and rheumatology clinics, and we would like to continue providing similar outreach opportunities through our joint Teen Backpack Program.

TAPC is committed to protecting participant privacy. Personal and medical information is collected, stored, and used only for program administration, community engagement, and



organizational planning purposes. Information is handled confidentially, access is restricted to authorized personnel, and participant information is never sold or disclosed to third parties except as required for program delivery, with consent, or as otherwise required by law.