Caring Others Increasing Engagement in PACT (CO-IMPACT)
Study Toolkit (v.1.0)

Tools to increase patient and family supporter engagement in care for diabetes

The toolkit was developed as part of a Veterans Health Administration research study
VA Health Services Research and Development Grant IIR 14-074
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Introduction

Most adults with chronic health conditions like diabetes have family or friends who are regularly involved in their medical and self-care. These “family supporters” are an important resource who can help improve patients’ engagement in their care and health outcomes. However, healthcare teams often lack structured and realistic approaches to work with family supporters of their patients effectively.

This toolkit contains information and tools that can be used by healthcare professionals, family members, or patients who are interested in helping patients’ family or friends get more involved with patients’ healthcare. These materials were developed for a program for adults with diabetes, but they can be helpful for any adults managing health conditions. Materials in this toolkit can be used separately as useful for patient care, or in combination to create a program that includes family supporters in patient care.

The goal of the CO-IMPACT program and its tools is to strengthen links between adults with diabetes and a family member or friend and give them skills to work together to help the patient reach their health goals. In the CO-IMPACT program, we called the family member or friend a “Care Partner.”

The main components of the CO-IMPACT intervention are below. For each of these components, we describe its purpose, and how it was used in CO-IMPACT, how other healthcare providers might use these components, and tips on best practices for using tools from our experienced CO-IMPACT coaches.

<table>
<thead>
<tr>
<th><strong>Initial session</strong></th>
<th>The coach met once with the patient and Care Partner for an hour to get the family up to speed on the patient’s diabetes-related care and teach the pair how to set and follow-through on patient health goals.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Handbook</strong></td>
<td>The handbook contains pages summarizing all the topics covered in the Initial session, general information about diabetes care, and worksheets and logs for home use.</td>
</tr>
<tr>
<td><strong>Visit preparation</strong></td>
<td>Prior to a patient’s primary care appointment, the coach called to help the patient prepare so that their appointment was as helpful to them as possible.</td>
</tr>
<tr>
<td><strong>Automated phone calls</strong></td>
<td>Every two weeks, the patient received an automated call that asked about key home diabetes management tasks, identified potential issues, gave automated feedback to patients and Care Partners with suggested ways to help the patient, and encouraged the pair to create action plans to address the issue(s).</td>
</tr>
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</table>

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Why Involve Family Supporters in Diabetes Management?

Adults who have more family support for their health care are better able to stick to their daily healthcare regimen, and they have better health (with fewer complications) in the long run. Importantly, most adults with chronic health conditions want their healthcare providers to involve their family supporters in their care.

Among adults with diabetes who do not have significant physical or memory impairment, between half and three-quarters have ongoing family member involvement in their medical management. Typical tasks include:

- Managing and using medications
- Checking sugar or blood pressure at home
- Making day-to-day decisions about self-care or illness care
- Tracking clinician recommendations and sending to other providers
- Health system navigation

In a study of Veterans with high-risk diabetes, we found:

- Over half had a family member who regularly helped them prepare for medical appointments
- Over half did not write down questions to bring to visit
- Almost 3/4 regularly discussed the medical appointment with a family member afterwards, but nearly 80% were not confident they remembered the content of the visit correctly.

In surveys and interviews of family supporters of adults with diabetes, many reported feeling limited by:

- Not knowing what questions to ask the patients on a day-to-day basis about their diabetes
- Lack of information about:
  - the patient’s health status (for example, blood test results)
  - what healthcare providers are recommending to the patient (for example, changes in medication regimen, recommended tests)
- Lack of confidence in helping with medications and home sugar meters

Read more about this topic in our paper

- Rosland et al, Diabetic Medicine, 2016

Read more about this topic in our papers

- Lee et al, Diabetes Care, 2018

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The CO-IMPACT Approach to Family Supporters

The ultimate goal of the CO-IMPACT study was to provide primary care teams with evidence-based, structured approaches to working with patients’ family supporters that improve patient engagement in care and health outcomes for adult patients with diabetes.

The CO-IMPACT study aimed to increase:

- Communication of patient-specific medical information and plans between the supporter-patient-primary care team
  - Positioning the patient as the leader of his or her health care team, with supporters as part of the team
  - Orientation to ‘who’s who’ in primary care and best way to reach them
  - Distinct and personalized after-visit summary with clear way to follow-up with any questions
  - Clear methods to get patient information and family questions to and from the primary care team
  - Access to information on how to handle diabetes ‘medical’ issues at home

- Use of effective supporter techniques and tools to support patient participation in diabetes care
  - Skills training in promoting and supporting patient-centered (autonomy supportive) and patient-engaged care
  - Tools for structured pre, post, and between-visit discussion between supporter and patient
  - Enable supporters to participate entirely from a distance

The program intentionally did not use the word “caregiver” for family supporters. Although similarities exist, supporters differ from caregivers in that they may not have a role of “taking care of” the patient. Instead, their role is to support the patient in diabetes management while respecting the autonomy of the patient.

The patient is ultimately in charge of his or her health and should be in control of making decisions and taking action. Supporters can still play a critical role in helping the patient manage the condition—but without taking charge. A critical component of the program was providing skills training in how to be supportive and communicate in ways that support patient autonomy in ultimately making their own healthcare decisions.
Fundamentals of Patient-Family Supporter Partner Teamwork

The following files contain education materials extracted from the CO-IMPACT patient handbook and website. These files could be used as handouts for providers, patients, or family supporters. We recommend that they be used in conjunction with education; after going over the content, recipients can take the handout with them for future reference.

Education and tips for providers working with family supporters (2 pgs.)

Background statistics on involving family supporters in adult diabetes care
- Potential benefits to providers of involving family supporters in patient care
- Tips on interacting with family members during provider appointments or phone calls

Guidelines for weekly patient-family supporter talks about diabetes (1 pg.)
Written for the patient and family supporter
- Recommends that the patient and supporter speak weekly about diabetes
- Guidelines for successful talks including:
  - Setting a day and time to speak each week
  - Planning to speak for at least ten minutes
  - Focusing on diabetes and limiting distractions
  - Writing a list of topics you want to cover before talking

Patient-supporter teamwork tips for patients (2 pgs.)
Written for the patient and advises the patient to:
- Keep the focus on you (the patient)
- Listen respectfully to your family partner—even if you disagree
- Be honest—no one is perfect
- Try to come up with ideas and solutions to problems together with your family supporter
- Create action plans that include ways your family supporter can help

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Patient-supporter teamwork tips for family supporters (6 pgs.)

Written for the family supporter and advises family supporters to:

- How to get conversations about diabetes flowing
- About the role of the family partner
- Do’s and Don’ts that emphasize support for the patient’s autonomy
- Examples of supportive family comments
- Additional ways the family supporter can help with diabetes care

Patient and supporter roles interacting with healthcare providers (8 pgs.)

- 1 page about patients’ role as an active part of the health care team
- 2 pages for patients on tips for getting the most out of appointments
- 3 pages for family supporters on benefits of attending appointments and tips for getting the most out of patient appointments
- 1 page for patients on how to follow-up on plans made during appointments, and when to call providers between appointments
- 1 page for family supporters on how to help patients follow-up on plans made during appointments, and deciding when to call providers between appointments
Initial Patient-Family Supporter Coaching Session: Script and Visuals

Purpose

This one-time health coaching session helps get the family supporter up to speed on the patient’s diabetes-related care, and it teaches the pair how to set and follow-through on patient health goals.

How this fit into the CO-IMPACT program

To kick off the program for a pair, the CO-IMPACT health coach met with the pair in an in-person session that lasted 60 minutes. If the Care Partner was unable to attend in person, they could participate via speakerphone.

The agenda for this session included

- Review the patient’s diabetes complication risk status: last HbA1c, blood pressure, lipid levels, and smoking status
- Review the patient’s latest diabetes plan based on medical record progress notes and prescriptions
- How patient-supporter pairs can use patient-centered goal-setting and SMART action planning together
- How supporters can use communication that is positive and supports the autonomy of the patient (and avoid communication that is overly nagging or criticizing)
- Specific prompts for supporters to use in regular discussions with patients about their diabetes and their action plans
- Orient family supporter to who is on the patient’s primary care team, their roles, and how to reach them. Explain the roles of specialized team members, such as pharmacists and dietitians.
- Techniques for effective patient and supporter communication with patients’ medical providers
- Educate pairs about available diabetes risk reduction programs

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How healthcare providers can adapt this component

Healthcare providers, such as nurse care managers or diabetes educators, could complete the full health coaching session with the patient and family supporter pair, or they could use selected sections and materials they believe would be most beneficial to the patient or supporter.

Materials

<table>
<thead>
<tr>
<th><strong>Diabetes health summary sheet template (Word file, 2 pgs.)</strong></th>
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</table>
| • Patient’s diabetes complication risk status: last HbA1c, blood pressure, lipid levels, and smoking status  
  • Patient’s latest diabetes plan based on medical record progress notes and prescriptions |

<table>
<thead>
<tr>
<th><strong>Initial session full coach script (Word file, 25 pgs.)</strong></th>
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<tbody>
<tr>
<td>• See agenda above for content covered in the script</td>
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<table>
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<tr>
<th><strong>Initial session full slide deck for participants (PowerPoint file, 63 slides)</strong></th>
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<tr>
<td>• See agenda above for content covered in the script</td>
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<table>
<thead>
<tr>
<th>‘Best Phrase’ Activity (Word file, 14 pgs.)</th>
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</table>
| • Purpose of activity is to reinforce five tips on how family partners can supportively communicate with the patient about their health habits  
  • One side of each card is an example of a better way to communicate with the patient; the other side is a less effective way.  
  • File includes a short description of the activity, a script for the facilitator, the key to the correct phrases (which are color-coded to indicate which tip the phrase exemplifies), and the text for creating 12 color-coded, double-sided cards. |

<table>
<thead>
<tr>
<th><strong>Patient-Family Supporter Handbook</strong></th>
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<tr>
<td>• Described in the next section</td>
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</table>
Recommendations from CO-IMPACT coaches on using these materials

- Many family supporters and patients find the patient diabetes risk information interesting and thought provoking. Many felt like they had never gotten a clear picture of where they (or their loved one) stood in terms of things they could do to lower their risk of diabetes complications. Health coaches presented the information, then followed the pair’s lead on which parts to discuss further. This is an engaging section where the provider can start a 3-way conversation with the pair and gauge the patient and family member’s knowledge about diabetes. The coach can also note the items the pair find interesting to use later as suggested areas for a first Action Plan.

- The session was designed with a motivational interviewing spirit in mind. Participants are asked open ended questions whenever possible and given affirmations for any level of engagement with the material.

- Focus on the pairs’ strengths by focusing on things that the pair is already doing well. Then help them think of ways to build on these strengths to work better together.

- This session covers a lot of material. If feasible, consider splitting the content into two sessions so that the sessions are more interactive, and so the pair has time to share their thoughts and experiences and to absorb and reflect on the material.

- Facilitators can model the communication techniques that are taught in the session when talking with the pair and point out and praise instances when one person in the pair demonstrates such communication during the session.
Patient-Care Partner Handbook and Website

Purpose
This handbook contains pages summarizing all the topics covered in the Initial session, general information about diabetes care, and worksheets and logs for home use.

How this fit into the CO-IMPACT program
The handbook and website link were given to the patient at the initial coaching session. The coach provided an overview of its contents at the session. In addition to reinforcing the content covered in the initial session, the handbook contains information on diabetes care that patients were asked about on their twice-monthly automated calls. If the call identified any issues, the automated call reminded the patient that there was more information in the handbook, and the Care Partner received an email with links to website pages about the issues flagged by the call. The final pages of the handbook contained worksheets and logs that we encouraged patients to use.

Handbook sections

<table>
<thead>
<tr>
<th>Diabetes Health Information (33 pgs.)</th>
<th>Action Planning (10 pages)</th>
<th>Patient – Care Partner Teamwork (9 pgs.)</th>
<th>Partnering with Healthcare Providers (13 pgs.)</th>
<th>Worksheets and Logs (23 pgs.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>o Sick days</td>
<td>o Planning to Make Healthy Changes</td>
<td>o Patient-Care Partner Teamwork</td>
<td>o Partnering with Healthcare Providers</td>
<td>o Weight, blood pressures, and blood sugar log</td>
</tr>
<tr>
<td>o Sugar levels</td>
<td>o Make a SMART plan</td>
<td>o Tips for Patient Partners: Talking with Care Partners about Health</td>
<td>o Getting the most out of appointments: for patients</td>
<td>o Medication Chart</td>
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<tr>
<td>o Blood pressure</td>
<td></td>
<td>o Tips for Care Partners: Getting the Conversation Flowing</td>
<td>o Getting the most out of appointments: for care partners</td>
<td>o Action Planning Worksheet</td>
</tr>
<tr>
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<td>o Tips for Care Partners: For a Positive and Helpful Conversation</td>
<td>o Between Appointments: For Patients</td>
<td>o Patient Event Log</td>
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<tr>
<td></td>
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<td></td>
<td>o My HealtheVet (How to access VA’s online patient health portal)</td>
<td>o Visit Planning Worksheet</td>
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<td></td>
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<td>o Getting Medication Refills in the VA</td>
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<td>o Emergency Care in Non-VA Facilities</td>
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<td></td>
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<td></td>
<td>o VA Programs and Classes for People with Diabetes</td>
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</table>

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How healthcare providers can adapt this

Providers may want to give sections of the handbook to patients and/or Family Supporters as educational materials. We’ve provided the handbook as one large PDF with a detailed table of contents as well two smaller files of the two key sections.

Materials

- **Full Handbook (PDF, 116 pgs.)**
- **Key Sections:**
  - Patient-Care Partner Teamwork (Publisher, 9 pgs.)
  - Partnering with Healthcare Providers (Publisher, 14 pgs.)
- **Worksheets and logs**
  - Click for PDF files

Recommendations from CO-IMPACT coaches on using these materials

- Patients and family supporters really liked the worksheets and logs found at the end of the handbook. Consider giving them multiple copies of the logs to take home.
- The worksheet used for planning for primary care appointments can be used as a stand-alone tool, or during the visit planning calls described in the next section.
- Stress that the handbook has a lot of useful information and suggest they store it in a location that makes it handy for future reference. This is especially helpful if the patient will be engaged in an ongoing program such as weekly talks with their family supporter, visit preparation calls, or automated monitoring calls.
- If patient and family supporters do not live in the same home, give a handbook to both patient and family supporter.
Visit Planning Calls: Script and Worksheet

Purpose
The purpose of the Visit Planning phone call was to help the patient prepare so that their upcoming primary care appointment was as helpful to them as possible.

This included:

- Reminding the patient of the details of their upcoming primary care appointment
- Teach the patient how to identify, prioritize, write down, and bring to the visit their main questions and concerns that they want to bring up with their provider
- Coach the patient on how to best bring up their main questions or concerns
- Involve the family supporter in the process of preparing for appointments (when possible) and help the patient identify the ways in which he/she would like the supporter to be involved in the visit

How this fit into the CO-IMPACT program
The visit prep calls were completed about a week before patient had a primary care appointment. The patient’s health coach would call the patient to see if they had 10-15 minutes to prepare for their primary care appointment. If the patient was available, the health coach would ask the patient to have their worksheet or a sheet of paper and pen available and ask if the family supporter was available to join the call. If the supporter was available and the patient agreed to their participation, they would join on speakerphone or on another phone on the same line.

How healthcare providers can adapt this

- Introduce the concept of visit preparation to the patient and family supporter. Print out and give the patient “Getting the most out of appointments” and a few copies of the “Visit Planning Worksheet”
- If resources permit, assign someone on the care team to call the patient to assist them in preparing for the visit. Let the patient know to expect the call.
- Consider triaging who would most benefit from the visit planning calls – those with recent health events such as hospitalizations, changes in their medical regimens (such as new medications), or those doing active home monitoring may particularly benefit.

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Materials
During the call, the health coach followed a guide (available below) and coached the patient in completing the diabetes visit planning worksheet, which was included in the handbook and available below. Patients were encouraged to bring this worksheet with them to their medical appointment and use it while they talk with their healthcare provider. Also provided here is a section from the handbook on “Getting the most out of appointments.” Some pages are directed towards patients, while others are for family supporters; headers are included to make the intended audience clear.

Guide to visit prep calls (for the healthcare professional’s use)

Diabetes visit planning worksheet (Word, 1 pg.)

Getting the most out of appointments (Publisher, 7 pgs.)

Recommendations from Coaches

- Patients got the most out of these calls when they were able to write down their ‘agenda’ for their medical visit during the call. The coaches found that many patients would answer the phone and wanted to complete the call, but they were driving or did not have access to a pen and paper. In this scenario, the coach would complete the call with them, but encourage them to write down everything as soon as they could.

- Use motivational interviewing techniques whenever possible. In particular, try to ask open-ended questions rather than yes/no questions. For example, patients would be more engaged if the coach asked, “How have things been going with your diabetes?” rather than “Did you check your sugar this week?”

- Encourage the patient to ask the family supporter to join the call when possible. If not possible, at the end of the call encourage the patient to go over the worksheet with their supporter and ask their supporter if they have anything to add.

- Encourage the patients to place the completed worksheet in a place where they will not forget it to take to their appointment.

- Encourage the patient to also collect in the same place any other paperwork they need to take (testing results, referrals, etc.).
Automated Phone System  
(possible future App or Texting program use)

**Purpose**
The purpose of the automated calls is to identify diabetes management concerns that patients could focus on in creating action plans, and to prompt continued action planning and family supporter involvement between primary care visits.

**How this fit into the CO-IMPACT program**
Patients received an automated call lasting 10-15 minutes once every two weeks. During the call, the patient was asked to report on diabetes self-management activities such as recent blood sugar and blood pressure readings, supply of prescribed medications, and foot problems.

Questions were automatically tailored based on responses in order to provide positive feedback or identify potential issues and provide issue-specific recommendations. When an issue was identified, the patient was asked if they wish to work on addressing the issue over the next two weeks, and if so, they were encouraged, at the end of the call, to make an action plan with their supporter to address their concern.

Following the call, the system generated a summary of what was reported, issues identified, which issues the patient wished to work on, and advice on how the family supporter could help the patient with the issue. This summary was either e-mailed or mailed to the supporter.

**How healthcare providers can adapt this**
- This script could be adapted for an automated phone call, SMS (texting), or a smart phone app system
- The tips included in the summary messages to family supporters can be incorporated into in-person healthcare appointments or phone calls that include supporters.
Materials

If you are interested in seeing the full script for the automated calls and summary messages for supporters, please contact our team at complexcaring@pitt.edu.

<table>
<thead>
<tr>
<th>Graphical flow of automated calls (2 pgs.)</th>
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<tbody>
<tr>
<td>• High-level flowchart of topics addressed during automated calls</td>
</tr>
<tr>
<td>• Detailed flowchart of one example topic (high sugar levels)</td>
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</table>

<table>
<thead>
<tr>
<th>Example from automated call script (5 pgs.)</th>
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<tbody>
<tr>
<td>• Sample automated call script for one topic (high sugar levels)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Example summary email for family supporters (3 pgs.)</th>
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<tbody>
<tr>
<td>• Sample of summary sent (via mail or email) to family support after a completed call</td>
</tr>
</tbody>
</table>

Recommendations from Coaches

• Some family supporters in our program used email but many did not. Users should try to identify what modes of communication (mail, email, text, recorded phone message) supporters in their population would prefer.

• Some patients grew bored with the phone script as the topics did not change over several months. One helpful approach was allowing patients to put calls on hold for a month or two, or until patients returned to actively working on changing their home regimen. Future adaptations of this script could consider changing content or frequency of calls in response to the pattern of patients’ responses.

• We would follow-up with the patient if they missed 3 consecutive calls. It could be because they got a new phone number, the time no longer worked for them, or they accidentally blocked the number.
Additional Information

Protocol publication

• Engaging Family Supporters of Adult Patients with Diabetes to Improve Clinical and Patient-Centered Outcomes: Study Protocol for a Randomized Controlled Trial (Trials, 2018).

Links to VA Caregiving Websites

• The Program of Comprehensive Assistance for Family Caregivers from the US Department of Veterans Affairs.

• VA Caregiver Website

Fundamental Publications/Resources

• Online resources for family caregivers of cognitively competent patients: A review of user-driven reputable health website content on caregiver communication with health professionals (Keast, et al, 2020)

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